

**THE CASH AND COUNSELING QUALITATIVE STUDY:
STORIES FROM THE CONSUMER-DIRECTED CARE
PROGRAM IN FLORIDA**

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Table of Contents

Executive Summary	1
Introduction	2
Methodology	
<u>Purpose</u>	2
<u>Design</u>	3
<u>Sample</u>	4
<u>Data Collection/Interviews</u>	4
<u>Analysis</u>	5
<u>How We Wrote the Stories</u>	5
Consumer Stories	
<u>Consumer Story 1</u> : Cynthia Jansen, 77 year-old White female, non-family PCW, no representative.....	7
<u>Consumer Story 2</u> : Eva Burris, 87 year-old White female, family PCW, representative.....	13
<u>Consumer Story 3</u> : Bruce Newman, 81 year-old White male, family PCW, representative.....	32
<u>Consumer Story 4</u> : Pamela Morris, 52 year-old, White female, family PCW, no representative.....	39
<u>Consumer Story 5</u> : Regina Erdman, 55 year-old White female, family PCW, no representative.....	49
<u>Consumer Story 6</u> : Richard Trappani, 39 year-old, White male, family and non- family PCW, no representative.....	62
<u>Consumer Story 7</u> : Caroline Dunlap, 63 year-old, White female, family PCW, representative.....	69
<u>Consumer Story 8</u> : Marta Covas, 37 year-old, Hispanic female, family PCW, representative.....	74
<u>Consumer Story 9</u> : Marilena Arroyo, 27 year-old, Hispanic female, family PCW, representative.....	81

<u>Consumer Story 10</u> : Kent Joyner, 43 year-old, White male, non-family PCW, no representative.....	86
<u>Consumer Story 11</u> : Paul Farmer, 10 year-old, African-American male, family and non-family PCW, representative.....	93
<u>Consumer Story 12</u> : Sarah Sullivan, 8 year-old, White female, family PCW, representative.....	98
<u>Consumer Story 13</u> : Adam Connolly, 26 year-old, White male, non-family PCW, representative.....	112
<u>Consumer Story 14</u> : Nora Bennett, 98 year-old, White female, non-family PCW, representative.....	121
<u>Consumer Story 15</u> : Julia Lynch, 89 year-old, African-American female, family PCW, no representative.....	130
<u>Consumer Story 16</u> : Wallace Beal, 71 year-old, African-American male, family PCW, no representative.....	137
<u>Consumer Story 17</u> : Lynette Gabriel, 35 year-old, African-American female, family PCW, representative.....	144
<u>Consumer Story 18</u> : Yolanda Benavides, 11 year-old, Hispanic female, non-family PCW, representative.....	151
<u>Consumer Story 19</u> : Jay Andrews, 7 year-old, African-American male, non family PCW, representative.....	158
<u>Consumer Story 20</u> : Bonnie Aguilar, 5 year-old, Hispanic female, non-family PCW, representative.....	164
<u>Consumer Story 21</u> : Ian Scofield, 33 year-old, White male, non-family PCW, representative.....	169
<u>Consumer Story 22</u> : Jenny Hollins, 11 year-old, African-American female, family PCW, representative.....	174
<u>Consumer Story 23</u> : Nikki Cannon, 53 year-old, African-American female, family PCW, no representative	178
<u>Consumer Story 24</u> : Dwight Brown, 9 year-old White male, family PCW, representative	187

Discussion of Cross-Cutting Topics and Themes

The Caregiver Relationship196

The Skills and Qualities of Caregivers198

Physical Problems As a Result of Caregiving199

Previous Experience with Agency Workers200

Relationship with Consultant202

Alternate Uses of the Cash Benefit203

Problems with the Program207

Benefits of the Program208

Appendix A

Case Selection Criteria.....211

Appendix B

Interview Protocols

Consumer-Representative Protocol..... 212

Family Care Worker Protocol..... 220

Non-family Care Worker Protocol.....227

Counselor Protocol.....233

Executive Summary

The following report presents twenty-four case stories about the experience of adults and children with disabilities who receive the cash option in the Consumer Directed Care Program in the state of Florida. The report focuses on how “care units,” composed of consumers and/or representatives, paid workers, and consultants interacted around issues of consumer-directed care. The study addresses several broad research questions: (1) has the Consumer Directed Care program made a difference in the lives of consumers, representatives, and workers, and if so, how; (2) how does participation in the Consumer Directed Care program compare with previous arrangements; (3) how are services provided; and (4) how does the program work? Two University of Maryland Baltimore County (UMBC) researchers conducted a total of fifty-eight interviews on one trip to Florida during July and August of 2002. After consultation with the Cash and Counseling Demonstration and Evaluation (CCDE) management team, twenty-four care units were selected. All the consumers interviewed had been enrolled in Florida’s Consumer Directed Care program for at least six months at the time of the interview and received at least six hundred dollars per month in the cash option. Care unit members were interviewed in face-to-face, hour long interviews which were tape-recorded for later transcription. The stories in the report were written based on the transcripts and incorporate the perspectives of all three members of the care unit; consumer, caregiver, and consultant. Major themes in the stories are discussed at the end of the report. The project was funded by the Office of the Assistant Secretary for Planning and Evaluation- Department of Health and Human Services and the Robert Wood Johnson Foundation.

Introduction

The following report presents twenty-four stories about what it is like as an adult or a child with a disability to participate in the Consumer Directed Care program (for a detailed discussion of the Cash and Counseling Demonstration and Evaluation of which Florida's Consumer Directed Care program is a part, see the project website, www.cashandcounseling.org). Researchers from the University of Maryland, Baltimore County (UMBC) traveled to Florida to interview participants about the program and how it worked for them. In their own words we learn what it is like to arrange and pay for your own care with or without a representative's help, how participants direct and pay their caregivers, and how participants negotiate the program itself. The twenty-four stories presented here also yield common themes and concerns which help us understand how the Florida Consumer Directed Care program works and the meaning it has for participants.

Methodology

Purpose

The purpose of the qualitative study was to provide detailed information and stories about the experiences of participants receiving the "cash option" in Florida's Consumer Directed Care program. The study focused on how "care units," composed of consumers and/or representatives, paid workers, and counselors interacted around issues of consumer directed care. The study addresses several broad research questions: (1) has Consumer Directed Care made a difference in the lives of consumers, representatives, and workers, and if so, how; (2) how does participation in the Consumer Directed Care

program compare with previous arrangements; (3) in what manner are services provided, and (4) how does the program work?

Design

Following the approach taken by Keigher and Luz², the focus was on both consumers (Consumer Directed Care participants and their families) and their paid workers (both family and non-family member workers). Additionally, interviews were conducted with state consultants assigned to provide oversight for those consumers and are included as part of the care unit interviews.

Qualitative data collection (involving interviews, visits to consumers homes, and travel throughout the state) took place in Florida in July and August 2002. Face-to-face, semi-structured interviews lasting about one hour each were conducted with the members of 24 care units. The tape-recorded interviews were conducted by two trained interviewers and took place in the consumers' homes. One of the interviewers was able to interview participants in Spanish when necessary. Each consumer interviewed had participated in the Florida Consumer Directed Care program for at least six months. Consumers of different ages (including children under 18), races, genders, monthly cash benefit amounts, and type of care workers were interviewed.

Three semi-structured interview protocols (consumer/representative, paid caregiver, and counselor) were developed through an iterative process of consultation with the Cash and Counseling Program management team (included representatives from the National Program office, Mathematica Policy Research, Consumer Directed Care

² *Keigher, Sharon M. and Luz, Clare. (1997). A Pilot Study of Milwaukee's Gray Market in Independent Care: Common Stakes in Homecare of the Elderly. School of Social Welfare, University of Wisconsin-Milwaukee*

Program in Florida, Assistant Secretary for Planning and Evaluation-U.S. Department of Health and Human Services, and the Robert Wood Johnson Foundation). Interviews included open-ended questions organized under three headings: background, services, and operations of the program.

Sample

Selection criteria for the care units (triads including consumer/representative, paid worker, and counselor) were developed in close consultation with the Management team and the Florida program office. Four main selection criteria were identified as: age 0-17/18-64/65+, ethnicity African American/Hispanic/White, type of worker family/non-family, and representative/no representative. Other variables taken into consideration to ensure maximum variability were county of residence, variations in use of the cash benefit, disability level (determined by level of Medicaid benefit, but above \$600 per month), gender, and language. The Florida sample included children with disabilities under 18 years of age.

The names of eligible consumers (i.e., had participated in the program for at least six months and fitting the selection criteria) to contact were derived from lists provided by Mathematica Policy Research and Florida program office. Research staff then telephoned potential subjects to enlist their participation and schedule home visits to conduct interviews.

Data Collection/Interviews

A total of 58 interviews were conducted (24 care units composed of 46 consumers/representatives and paid workers, and 12 counselors). Two female interviewers made one visit to Florida in July and August 2002 to conduct the interviews.

All interviews with consumers and paid workers were face-to-face and conducted in the home of the consumer. In most cases, consumers and paid workers were interviewed during the same visit. The representatives of children with disabilities were interviewed. In many cases the child was present at the interview and participated in answering questions. Interviews averaged about one hour and were tape-recorded.

Twelve counselors were interviewed by phone at a later date. Counselors were asked about their activities as counselors in the Consumer Directed Care program generally, and specifically, about the consumers in the study for whom they were responsible.

Analysis

Individual tape recordings were transcribed verbatim as Word documents. Stories were written from the three interview transcripts in each care unit.

How We Wrote the Stories

We wrote each of the twenty-four stories based on related interviews with a consumer, personal care worker, and counselor. In writing the stories, we tried to incorporate all three perspectives on a topic or story whenever possible. Each story relies heavily on direct quotations with a limited amount of our writing to connect the narrative. We also used the interviewers' case summaries to add detail to the stories.

Occasionally, the facts or chronologies were not clear or were in conflict with the information in other interviews within a unit. In some cases the discrepancies came about because of a time lag between interviews, differences of viewpoint about the topic, or a lack of knowledge on the part of a member of the unit. In cases where facts were

unclear or contradictory, we checked the interviewer's notes and reconciled evidence within the transcripts themselves.

One author wrote the original story drafts. The accuracy of the stories were checked by a member of the team who conducted the interviews. We added topic headings in each story to facilitate reading and comparison between stories. Names are all pseudonyms. Places, companies, and agency names have been eliminated or fictitious names used in their stead.

Within quotations, three periods represent a short break within an answer such as an interviewer breaking in to ask a question. Four periods are used to indicate a considerable break in the conversation. For example, sometimes a consumer returned to a topic or expanded on an answer much later in an interview. Parentheses within a quote include our clarification of a reference to a person or event. The terms caregiver, care worker, and care provider were used interchangeably as were consumer and participant.

Quotations were rendered as close to verbatim as possible in order to preserve the rhythm and regional flavor of the interviewees' speech patterns. Above all, the participants speak for themselves about what life is like for them in the Consumer Directed Care program.

Consumer Story 1

Mrs. Cynthia Jansen is a widowed, 77 year-old white woman who lives alone in an apartment in the Tampa area. Mrs. Jansen was neatly groomed, dressed in a housecoat and slippers. She was interviewed while seated in a recliner in the living room of her three-room apartment. The apartment was well lit, clean, and organized. There were paintings and photos on the walls, and the ceiling fan was on. She greeted the interviewers with a warm smile and was pleasant and attentive during the interview. She seemed to enjoy the company.

From her position in the recliner she had a view of every room in the apartment: kitchen, bathroom and bedroom. The television remained on throughout the interview. She had TV trays on either side of her, one for her medications and one for her tissues, water, TV Guide, and remote control. She was surrounded by medical devices to help her breathe, including a nebulizer, an oxygen tank, and an oxygen mask and tubing. She had some trouble catching her breath while she was speaking. At the time of the interview, Mrs. Jansen had no care worker. The new care worker was to begin the following day. Her previous care worker is continuing to check on her until the new care worker begins. Before we started the interview she mentioned that she was very happy with the CDC program.

The consumer did not refer much to her family and in fact, said that there was “no one” when asked about family care workers. The consumer is reliant on her friends, neighbors and her care worker for assistance with her daily living needs. She does have a walker and a scooter to help her move around in and outside of the house. Mrs. Jansen mentioned that she was not able to get out of the apartment on her own. Her son had

installed some bars in the shower in order to help her when bathing. She did not seem to be bothered by the fact that she could not leave the apartment without assistance. She did mention that she has friends who come and take her to lunch or dinner occasionally. Mrs. Jansen remains at home watching television most days. She was very interested in learning more about the program, and was convinced that the arrangements after her enrollment in the CDC program were definitely better than her previous arrangements.

Enrolling in the Program

Mrs. Jansen heard about the CDC program through a program for seniors in her county. She wanted to enroll because,

Well, it sounded good! It sounded good, you know! I wanted to stay here (in my own apartment) and I couldn't stay on my own... and I couldn't afford no wage to pay someone to come in steadily. I had some help but I had to cancel it.

Watching Her Health

Mrs. Jansen describes her health problems,

I have what they call COPD (chronic obstructive pulmonary disease). That's asthma, bronchitis, emphysema...so I'm on oxygen 24/7. I have congestive heart failure, diverticulitis, thyroid problems, parathyroidism, because of that I'm limited on dairy products. And now I have borderline diabetes. So I have to watch my fat... I have to watch my fluids. I'm only allowed 40 oz a day. I have to keep a schedule for the whole day. Every four hours I have to do my breathing with the nebulizer. Between the patch on the heart, it goes on in the morning, off at night. I've been trying to do the dishes but I have to sit down because I can't lay down.

The Most Important Needs

Mrs. Jansen describes the tasks she needs help with, "cooking, cleaning, helping me bathe and wash my hair, my laundry." She also needs someone to wash her dishes for her and make the bed. When she receives a delivery of medications she has to have the caregiver put it away for her. The caregiver helped her to set up the medication within easy reach on the trays next to her chair. Mrs. Jansen states that, "The most important

part is cooking and shopping for me. You could always get someone to come in and clean, but you can't talk." A personal relationship and conversation with a caregiver is also an important need in her view.

When she requires transportation to the doctor's she has a neighbor she pays or a transportation service she calls,

Not by myself. I have friends. Like Monday I had to go to the doctor's and my friend upstairs used to take me, but there's a man in here, he does it, I give him a few dollars and I paid for lunch with him too. But when I'm going to the heart doctor I call the transportation service number and they pick me up.

Caregiver Qualities

Mrs. Jansen looks for a caregiver who is "honest and personable." She supervises her own caregiver.

Caregiver History

Mrs. Jansen describes her previous caregiver,

I had one for five and a half years.... She was a friend, too, but she was recommended by this nursing service that I used to have that my doctor always recommends when I get out of the hospital... She was for two and a half years (with the CDC program) and before that I used to pay her myself. She's only given caregiving up now because she's been having some medical problems herself and she has a full time job, it's just too much for her.... That was a blow, but I can understand... She's a wonderful person... She had to go (to work) full time so she could have benefits. She stayed with (me) and she wanted to give it up even sooner, but she didn't want to give me a double whammy as she said it, with my good neighbor upstairs moving to be close to her children and she was a big help and so she waited.

In fact, she came in Friday, and she came in Monday to make sure I had food and Monday she went and she shopped and she cooked so I have a refrigerator full of good food now for the whole week. And then the other party starts Thursday. I had gotten someone else and then when she started filling out the paperwork she decided no, because she didn't want to pay Uncle Sam. I had to start from scratch again last week. It's only been two weeks since I was hanging.

The new caregiver who is due to start later in the week, “was recommended by the nursing service that I always had when it’s necessary, they recommended her. I know her name now but that’s all.”

Difficulty Finding Caregivers

Mrs. Jansen is waiting for her new caregiver to start work, “She was supposed to have started yesterday but she hurt her knee. So the doctor told her to stay off it, but she promised, she said I’ll be there Thursday so here’s hoping.” If her new caregiver does not come Thursday, Mrs. Jansen will try to get help in other ways, “I can call the girl that worked for me all those years. She told me that if she (the new worker) backs out or something that to call her and that she’ll still come.”

Mrs. Jansen has a strategy for finding a caregiver,

You just ask around. It’s not so easy. (If I need to find someone) I’ll call the nursing service, the head nurse, and ask her if she has anyone else because she’s the one who recommended this one and then I have feelers out other places, in fact I had called this one agency that was in the church bulletin. But in fact the agency was going to call my consultant about the payment because...they get a piece of the check, so it’s a problem of how that could be arranged and she didn’t know either so she was going to ask. I called her back and told her I got someone, but to call my consultant anyhow in case it comes up another time. But the way she explained it to me is \$8.50 of the check would go to the caregiver, and \$3.50 of the check goes to the agency. But the thing is that the check is made out to the caregiver, the whole amount. So this is what she didn’t know how this would work. I said I didn’t have no idea either. That’s why it’s always better for the person who’s going to work for you to come on their own.

Schedule and Pay

Mrs. Jansen describes the new caregiver’s weekly schedule,

She supposedly will come on Tuesdays for four hours and two other days for two hours so she’ll work 8-10 hours a week. She’ll be getting \$12.00 an hour. My consultant thought that I paid too much money in salary because the other girl got \$13.00. So I dropped it down to \$12.00 but that’s fine...to get anyone decent you have to pay for it! ... I use all my money going to the caregiver whereas, if you can get someone for cheap you can use it for other (purposes).

Use of the Cash Allowance

The interviewer asked her if the hand rails in her bathtub were bought with her cash allowance, but Mrs. Jansen responded,

My son put those up. Oh no, you are not allowed to do that...(use the money for hand rails) they said I could only use it for personal items [handrails can be paid for with the cash benefit-Ed.]. I use it for myself. I buy makeup and toilet articles and I use tissues...you see tissues all over the house.

Relationship with the Consultant

The consultant encouraged Mrs. Jansen to try the CDC program,

She's very nice and she's very helpful. She talked me into this program because I was a little afraid at first, it was so complicated, all the paperwork and all the stuff, you know...and she said "no, no, no." and she was right, once you get it going it's fine. If I have a problem I call her.

Mrs. Jansen's consultant describes her as being very independent and requiring a minimum of contact every month.

Outside Support

Mrs. Jansen describes volunteer help she receives from a church community,

There's a lady from the church comes in once a week and she's here for about two hours. Last time she cleaned out my pantry for me. Oh God! I can't believe it's the same place! And, you know she did the refrigerator, things that the other people don't...you know there just isn't enough time for them to do it. She only comes in for two hours and she's delightful. She brings me homemade eggplant that's out of this world! My neighbors here are wonderful, too.

Benefits of the Program

Mrs. Jansen describes why she likes the program, "The fact that I could stay in my own home was (what I like), I had a taste of the nursing home, was there for seven weeks...uuugghh." Mrs. Jansen states the most important advantage of the program, "Oh it's peace of mind, you know, it's nice to know the fridge is here and you have food ready

for you, the house is cleaned, it means a lot to me.” Another benefit is, “Staying home, in your own place and knowing that you’re going to be helped.”

Problems with the Program

Mrs. Jansen is very happy with the program. She feels that she could use more hours for caregiving, but she is “making do.” The timeliness of paychecks for caregivers is a problem, too,

It’s a little hard, they (caregivers) have to wait like a month before they get paid! So they (the program) pay every two weeks and then they hold back the first two weeks (at the start of the program) so I may have to do something there because they (caregivers) need their money. I may have to give her some of my money (until her check comes). The other one didn’t mind because she had another job and so she still has a check coming to her.

Consumer Story 2

Mrs. Eva Burris is an 87 year-old white widow who lives with her daughter and her family in a large one story tract home in a suburb of Tampa. The house is in a mixed residential area comprised of well-maintained homes intermingled with dilapidated homes and vacant properties. Mrs. Burris shares the house with an extended family; her daughter Susanna and her husband Bill, a granddaughter, and Rose, another grown daughter. Her daughter Susanna is her representative and caregiver. Until recently, Susannah was also caring for her Aunt who is 95 and suffering from Alzheimer's. Her Aunt now lives in a nursing home.

Although bed-bound and still in her pajamas at the time of the interview, Mrs. Burris was well groomed and alert. She was interviewed in her bedroom resting in her electric hospital bed. Her bedroom was sparsely furnished with a large bookcase and a dresser with a television positioned so that she could watch it from bed. There was one window in the room which overlooked the front yard and provided a nice view of the sky and shrubbery. The rest of the house was very well-maintained and spacious with an open-floor plan, fireplace, and outside, a large screened area with an in ground swimming pool.

Mrs. Burris was confused at first because she had not been told about the interview. Despite this, she greeted the interviewers warmly, remained fairly attentive during the interview, and seemed to enjoy the company. Susanna remained in the room at the start of the interview because she wanted to help "fill in the gaps" for her mother. Susanna did not allow her mother to answer the questions. In fact, most of Susanna's answers revolved around her role as a caregiver. Susanna was hesitant to leave her

mother, but agreed to be interviewed separately in the living room. After her daughter left, Mrs. Burris was able to speak for herself and answer most questions.

Mrs. Burris needs twenty-four hour care due to a stroke that left her bed-bound and totally dependent on others for her care. In addition to her daughter, she has a non-family care worker who provides twenty hours of care a week. During the interview, Mrs. Burris said that the most important thing for her is being with her family. While she seemed happy with the program and the fact that her daughter was caring for her in her home, she did express sadness at being left alone in her bedroom while the family was eating meals, watching films, or doing other family activities. When the interview ended, Mrs. Burris cried, held onto the interviewer's hand, and did not want to let go.

Medical Problems

Mrs. Burris comments that, "I feel good," but it is clear that she suffers from several serious medical conditions. Before the stroke that left her bed bound, Mrs. Burris describes what happened, "I had a heart attack and I didn't even know I had a heart attack." Susanna describes how she found her,

She actually had the heart attack here. She actually was with my granddaughter. It was when she was still walking with her walker and she just sort of collapsed. I was here. I might have been outside, working in the yard. I was the one who picked you up with your glasses all kittywhampussed and everything else, and then I called my husband from work and he came home and we both tried to pick her up. I'd already called 911, but we were trying to get her in a better position.

Mrs. Burris explains that her daughter takes care of all her medications.

Susanna describes what her mother takes,

She's on two high blood pressure medications, one iron pill, one pill for dizziness... And there's one other, then she has one for nausea, but that's just as needed and now, we take almost six Tylenol for arthritis daily. We take two in the morning, two at lunch and two in the afternoon. Mostly that's what hurts her the most. Her arthritis. Her legs crack. They can't pick her up by the shoulders.

She can't be picked up. That's why we have to use the (gait) belt because her shoulders actually crack and dislocate, the bones are so brittle. Her legs just grind and crackle when you just turn her in the bed. The arthritis is what stopped her from walking. Not the heart attack.

Mrs. Burris has also been hospitalized for blood transfusions.

Enrollment in the Program

Susannah heard about the program after her mother needed more extensive care,

She had a stroke and so then we got a social worker and then they put me in touch with a wonderful program and the counselor had given me a girl 20 hours a week to come in. I would run out and try to go to work at Wal-Mart different hours, because I could never get a girl to come at the same times. Then they didn't show up, we didn't have enough help here. I'd have to call in to work. So one day, I was telling the counselor, "Just pay me the 20 hours," (to provide care) even though it was nothing. I don't mean "nothing"—it's a help, but in the big scheme of life it's nothing. I said at least I don't have to try to run out and do something else and have strangers in my house. I mean I've had some strange people in my house.

The counselor suggested the Consumer Directed Care Program and Susannah enrolled her mother,

Because I had to take two leaves of absences (from work) a year at a time and then (I had to quit) And I had to stay home. So I didn't have a choice. I had to stay home or put my mother in a nursing home. And she's a person-person. She likes to have people around her and family around her... And she was mainly by herself and she really doesn't mind being by herself, but my mother did and we just didn't feel like that time it was an option. So the family always banded together. We're not high living people. We live in a nice home, but we also sold our old house to build it..., we built it with wheelchair facilities and wheelchair showers and everything for my aunt and for my mother. So it was it was like a four (of us) effort. My sister was divorced. I was divorced at the time. My mother had a little house. My Aunt had a little house and we just sort of put it all together. But it hurt when I had to quit work because I had my own bills and responsibilities that are not just the house, you know.

And not only that, I was administrator coordinator for a dentist for 9 years so when we came here, I just tried to go to work at someplace like Wal-Mart because they have night hours. They have in-between hours, and actually, Wal-Mart will work with you pretty good on circumstances. But it was getting ridiculous. The agency workers would walk in at 10. I'd have to be at work at 10:30. If they were 20 minutes late, I was late, but then they'd leave at the regular time. I

couldn't (continue to work) . . . it was more stressful to have to run out for those 20 hours and then when she became just totally (disabled), I said, it's just not worth it for me. It costs more money to run out and have to do clothes and have to do gas (than staying home). The only reason I really stayed trying to do it is because of insurance. Because I'm going to be 58 and I couldn't afford to drop health insurance. So then I married and luckily my husband picked me up for health insurance. But if not, I had no health insurance. That's why I did the leave of absences, because Wal-Mart allowed me to pay my health insurance. But then after the second leave it was done. That was it. They didn't owe me anything else.

The Importance of Family Life

Mrs. Burris describes why she likes living at home, "The most important thing is I like to be with my family."

Susanna has a long history of caring for her mother,

We have been taking care of mom for eleven years since the year my dad died, because she never drove a car, never wrote a check ; she was the homemaker, but seven years ago we moved here. We have been taking care of her since then. So she moved from semi-walking to just getting up with a walker, to total dependence.

Family is an important part of life for Mrs. Burris and her daughter, but it can also be stressful at times. Susanna describes the problems she and her family have had on outings,

The last thing we took her out to, was when my daughter was getting married and we took her to a big restaurant. We actually borrowed a van. We took her and I actually paid the aid to go with me because it was my daughter's shower and I was expected to do things that I couldn't do for her. She really got very tired, very fast, sitting two three hours in a chair that's not a bed. She wants to go and I understand that. When she gets there, she hasn't gotten over it because my mother has always been a little ill all her life. And she's always had people cater to her and come with her and sit with her and she's not used to going into a place where she's not the center of attention still and when things are going on, people come and "Hi, how are you" but they're into their little things with their kids or whatever, and so then she gets her feelings hurt and she's like "Why should I go, no one talks to me." I said, "You know, mother, I don't get to talk to everyone (either) Sometimes, I tell her when Monday comes, "I'm so glad Monday's here," because actually, we're better off when it's her and me in the day. The weekend, when all the grandkids are here, it's the same kind of thing. She hears people out

there having fun or talking, or whatever we're doing like cooking or cleaning house. Well, she can't be out there so she starts crying because she feels that people are not (paying attention to her). I think that's her worst problem. Because I think she makes herself sick. She would feel so much better if she would just accept it. I tell her this is the way it is. This is what we got.

Mrs. Burriss explains, "Everybody's having fun and you're sitting alone like a fool in your room. I don't care what anybody says." Susanna disagrees with her mother,

First of all, you're not sitting like a fool, and second of all, some of the time when people are "having fun," we're cleaning the house and washing clothes. Do you really think my granddaughter who's thirteen comes and sits on my lap with me? She's on the computer, she's in the pool, and I see them when they dump the towels in and say what do we have for lunch?

Even though Mrs. Burriss has a large and active family, she often feels neglected and left out of what is happening in the household, which is a source of stress to her and to her daughter Susanna.

Something You Expect to Do

Susanna describes the importance of caring for her mother at home,

My mother also gets to see her total family more, living at home because when my grandchildren come to see me, their great grandmother's here. Cause we're like five generations or four generations. And actually my daughter's going to be building (a house) up front. And, so it's my mother, me, my daughters and her daughters so it's like all four generations living on the same property. I lived next door to my mother for the whole time my dad was sick because my dad was sick with kidney dialysis for six years. We used to have to take him back and forth to the dialysis center so we had bought a house next door to my parents. My youngest daughter actually bought my mother's house when we moved out here and my oldest daughter bought my house when we moved out here.

(Caregiving) It's just something that you expect to do. It's not anything you'd think about. And you actually hope that it doesn't come to different points like that, but when it does, you just (do it).

Previous Experience

Susanna describes the agency workers who she had to deal with before her mother enrolled in Consumer Directed Care,

They got their boyfriends, they were on drugs, and they're up at the jail last night, but you know they are CNAs and they've passed their test and they pass their background test, but it's scary. As long as I had one person for a while it worked out and then she quit, and then I had five people in a row and it's hard.

....A lot of times when I left my mother, I could tell she was scared of the agency worker, but we didn't have any choice at the time. (With this program) You don't have to have strangers in the house that you don't know exactly, I mean we had a lady the last time that my mother ended up in the hospital from anemia. We had an agency worker in the house who invented a "zapper" and she was telling me how you put the zapper on you and it zaps the bacteria. Then she started bringing my mother food instead of the food that I had left for her and she went to my washing machine and told me what detergent to use, and one time I threw away coffee grounds, missed the garbage can a little bit and she... (went ballistic). But then I said, "ooohh kay, 'bout time to change people." She was very well meaning and she was actually the hardest worker that ever came. She would have scrubbed the floors if you had asked her. But she was way out in left field. And then she started taking vital signs, which they are not supposed to, only the registered nurse who comes does that.

One day she scared my Mom to death because she told her that her blood pressure was so low that she should be dead. So when I came in, everybody was in (a panic). The agency worker was going to call the hospital and I just said, "You don't call nobody. I'm the person you call. I'll call a registered nurse or I'll call 911." She argued so I had to call the agency and they had to talk to her on the phone.

Mrs. Burris says that her agency workers were nice.

Help and Company

Mrs. Burris says that she needs help with everything. And that her daughter

"helps me when I bathe." Susanna elaborates,

She doesn't walk so she has to use bathroom privileges in the bed with a bedpan and we dress her in bed and change the sheets in the bed. Now she used to be sitting up in this lift chair. When we got the chair, she was still trying at least to stand up with a walker which then we could get her to a potty chair and we'd stand her up and put her back. But the last time we did it, she fell and she weighs about 180 pounds and I'm short. So now we just sit in the chair. But a lot of times, we'll put her in it and she can sit in it in the day. But it's just gotten more difficult because when she has to go to the bathroom in that chair, it's very difficult in that chair and sometimes you don't have time to put the chair up to get the lift to put the lift back in the bed, so we've been tending to stay more in the bed lately.

Susanna needs someone to sit with her mother,

... She's never left alone in the house by herself. Ever. Any time at all, even if I have to get my granddaughter up here. Luckily, my town is small. Ten minutes, I can get to WalMart. Ten minutes I can get to the grocery store. Sometimes I have to go after a prescription. And in the summer sometimes I call my granddaughter here who is fourteen. The pharmacy calls me, I'm ready to get the prescription. My granddaughter always has my car phone. One time I ran to the grocery store and she called and said "Mom's got to go to the bathroom." I didn't know what to do. So I just left all the groceries, came home, helped her, went back and got my groceries and came back. You can leave a babysitter, but not everyone can do it. My neighbor next door says, "Any time you need me I can sit with your mother." I said, "You don't understand what sitting with my mother means." And I wouldn't expect somebody to do that. That's something you have to do out of love because it's your family or your parents or your children. If you are a CNA or a registered nurse or an LPN, you are doing that for a living.

Some people are very well meaning and some people would come and just sit which is fine. Most the time when I get somebody (we now have two people that are really good), that help me baby-sit and I just tell them that all they need to do is just be a companion and of course any needs she has while I'm not here. But you don't have to dust. You don't have to clean. You don't have to do anything like that. I'll take care of that. You just have to be a companion for somebody to talk to and somebody to be with while I'm out of here. Actually, that's (the help) I need the most. I don't have the time to sit and communicate with my mother all day long. I have too many other things to do. And she would like a lot more attention in that field... You can't offer the service and the companionship at the same time. There is just not enough of you to do it.

Susanna explains that her mother has always needed attention and care,

She has never, never spent a night alone in her entire life. When my dad went away on a business trip a couple of times, it was always expected that one of us would go and spend the night at her house. And when he died, we went to her house. She didn't come to our house. Because she's always had her little set ways. This is the first time she's ever lived anyplace else. And she says she lives with me, but she knows that when we first built the house, we said it was a joint effort, and it was all of our houses. So she doesn't live with me. I live with her, she lives with me and we all live with everybody else in the house....

My mother has a lot of fears, of just everything. She just grew up like that. She fears the dark. She fears everything. You're going to get on a plane, she thinks you're going to die on the plane. You go to the beach, she thinks you're going to drown at the beach. She has a lot of fears and those fears have stopped her from doing things some of the things that she always wanted to do.

Mrs. Burris adds, “Well, but I really have had a good life. A very good life...
That’s what I want, my family.”

My Daughter Does Everything

Mrs. Burris says that Susanna does everything for her. Susanna describes what she does for her mother,

I give her medications, I give her breakfast, I make up her lunch, I make up her supper. We wash her hair, we have all the equipment to wash her hair, in bed, we sometimes give just a sponge bath, or what we used to call Cuban baths... Last Saturday, we tried to get into the shower because our air conditioner went out last week and we had three days without air and it was just horrible. And it was three days that the temperature felt like it was a hundred and five, and so we tried to get in the shower, and it was a disaster, but my husband is going to try to make me a different kind of seat. I have a shower chair that you can actually roll in, but this one has a toilet seat on it. And you can’t leave people in that a long time showering without a having a problem... I tried to take her into the shower with the lift, but she nearly fell off the chair and then she got sick and dizzy and it was a real disaster. And then, we clean her room and wash her clothes. We usually do one to two loads a day. Because we strip the sheets every day and we strip the pads every day and we strip the clothes every day and try to keep it as nice-smelling as we can because I can’t stand nursing homes when you can smell urine and stuff. That’s a big job, trying to [keep everything clean] all day.

I buy all the stuff. On the 30th of the month I get in the car and I fill it up. I’ll get like eight things of diapers, four things of wipes, six things of gloves, five packages of the underpads, and her powders. I call in all her prescriptions. My husband works at WalMart, too, and he’ll bring the prescriptions home to me; if not, he comes home at 4:30. And at 4:30, if I have to get something at the pharmacy or something and he’ll stay here.

I know her so good that I know if her color is from white to pink to whatever because I see her every single day. I could tell if she’s dehydrated. I give her laxatives on my schedule because I know when she goes to the bathroom. I know what kind of bowel movements she has. I know if she needs a laxative, and sometimes I give her two because it’s been a couple of days because she doesn’t move. You have no movement, you don’t go to the bathroom. That’s why when you have an operation, the first thing you do is get on your feet and walk in the halls. If I know I have to be away on Saturday I don’t give her a laxative so my sister doesn’t have to change her, my sister actually gags and has to put things up her nose so she doesn’t breathe (if she has to change her)– she just never had kids...

Susanna tries not to ask her sister to help much because her sister works long hours, often doesn't feel well, and is not good at caring for their mother.

Schedule

Susanna describes her day,

The day usually starts about 8 o'clock (in the morning). Sometimes my mother sleeps later, and usually I'm finishing washing dishes about 9:30 (in the evening). It's not that I have to be there continuous, but it is continuous because even though she sleeps for two hours, it's not like I can say, well now I can go and do stuff I need to do. You can't because you have to constantly know what she needs, and like a couple weeks ago I was mowing the yard outside, and I was probably out for about an hour and when I came back she had diarrhea, and it was all over the bed. She gets upset, and I said "don't be upset – there's nothing you can do." I could walk out to throw trash and it could be a five minute thing. So most of it is mental that you know that if I take an hour nap, that's the time she'll call me ten times. There is never time, you have no time. You don't have any time.

And my sister is so bad off that I feel guilty leaving her with my mother and actually a couple weeks ago, I had to send my sister to my other aunt's house for a week because she about had a nervous breakdown. Her legs are hurting so bad, and her arthritis – she walks with a cane. She's only 55. And so it is very hard. She would spend at least an hour talking to my mother, and then she would do the last change of diaper at night and put her to bed so then I could spend a little bit of time with my husband. She feels so bad that she can't do it, but my sister said, "I just cannot take care of her anymore. I cannot take care of her." And I said, "Just go to our Aunt's house and stay there two or three or four days and calm down. And just like my vacation – I got married last year. I think I ended up taking nine days or ten. My husband had two weeks vacation. I couldn't leave my mother and sister alone any longer, and I called every night. It's like I said, you're never mentally happy where you are (because you worry about your responsibility).

Susanna is paid for 20 hours a week, but estimates that she works, "probably 10 hours a day if not more. Because, like I said, if she has to go to the bathroom at 9 or 10 o'clock at night, she calls my sister. And then my sister calls me." Susanna is always on call. Susanna enjoys the weekends when her grandchildren are around, but finds the conflicting expectations difficult,

Like I said, sometimes on Mondays when everybody goes and I say, “Oh, thank God, there’ll be peace in the house tomorrow. I can wash my clothes, I can clean my house.” It’s not that I don’t enjoy my family, because I do, but it is very hard because when my grandkids are out here, I want to sit out here and enjoy them and be with them, but yet I still have to have an ear (for my mother). Even if my grandchildren say “let’s go out and get a pizza,” I can’t go out and get a pizza...

Susanna says that her mother’s consultant helped them get extra money,

When the consultant visited us she says, “You looked frazzled.” And I said, “Well, I haven’t had my mammogram, I haven’t had my yearly appointment.” Besides, I don’t work. If I do go to an appointment then my sister has to stay and then she doesn’t get paid for working because she has to stay home, so we get a double whammy. So the consultant says, “What if I can get you like 8 hours (more help) a week? Would that help you?” That definitely helped!

Supervision and Pay

Mrs. Burris receives 25 hours of care at \$10 an hour. The family pays a non-family caregiver for the additional hours. Susanna supervises her own work for her mother and the non-family caregiver.

Susanna describes how they use the cash allowance,

I pay my bills. Same bills I had before I had to quit work, you know . . . car payment. . . Only thing good is now I can wear shorts and a shirt, don’t have to dress up in heels and stuff, don’t have to buy five and six dollar lunches which (helps a lot). I put one tank of gas in my car a month now. When I worked in Tampa, I put in a tank of gas-- maybe it would last a week. Maybe it wouldn’t.

Caregiver Experience and Future Plans

Susanna says that she has worked for doctors and dentists her whole life. She has been responsible for her mother for eleven years and has been her caregiver for two and a half years at the time of the interview. Susanna thinks about what she will do in the future,

Actually, I had thought about (my life) after my mother’s (death); . . . I’m only 58. There is nowhere I can go back to work now without starting at the bottom of something, and retire at 62 which really I don’t have the money to retire at 62. But with what they allowed me to make I can actually work at a WalMart now

and make full-time and still collect social security, so I planned on doing that, and I thought well maybe I'll go (since I've done caregiving so often) to one of the care agencies and do that versus trying to go back to work at WalMart.. I know I can't go back in the medical field because they're hiring just young girls... So there's no going back into my profession because it just wouldn't work.

Susanna thinks that working as a caregiver would be good work in the future,

I think that when you do other people that are not your family, you go in the house and you're there three hours and then you say goodnight and you leave, and then it's done. I really would think about maybe doing about some care for some clients after my mother, you know, passed away. I know I can handle it.

Caregiver Qualities

Mrs. Burris likes her daughter as caregiver,

I like everything about it, her being with me, because she's been very understanding.... My daughter is very precise. She does everything just right. I couldn't ask for more. I couldn't ask for more than her. That's all I can tell you... I just love having my daughter with me.... She's good at everything she does.

Susanna demurs,

I don't do everything right. We all have our moments. But, you know, for the most part she's a very modest person also and she always was, and she'd prefer family to take care of those needs instead of have a stranger take care of them.

Mrs. Burris describes what she likes in a caregiver, "I'd just like them to be very nice, very friendly, because I'm a friendly person."

The Emotional Cost of Care

Susanna describes the emotional cost of caring for her mother,

I go to bed a lot of times at night and I just cry and then I do my little prayer and say tomorrow, God, I'll wake up and I'm going to have all the patience of Job. Nothing my mother says is going to push my button. Nothing she's going to do will hurt my feelings... but the one thing I can tell people is don't suppress your anger and stuff because you cannot hold it in.

I mean you don't go kill somebody, you don't go batter them, but you have to verbally – if she can verbally use verbiage to me, I can use it back, and that's when she'll calm down. If she sees that I'm really mad, she'll (stop), but when

she starts feeling sorry for herself, she'll go on... "I can't help it if I love you too much and I can't..." I say "Mom, I love you, but you got to let people go and you got to let them live their lives. She would like to have us all put four beds in with her and sleep in the same bedroom. I'm serious.

I think we have a good relationship because she knows I love her and I'll tell you the truth, sometimes I hate it. I can't stand it, but it wouldn't be any other way. I don't think it's a good situation really sometimes, and probably all the time because, like I told her "Ma, at 58 my life's dream is not living in the house with my mother or taking care of my mother. It was to have my family and my husband, and enjoy my children. But that's not the way it is – this is the way it is. So why discuss it? There's nothing you can do about it." But it puts a lot of pressure on me and my daughters because they're not with me on a seven day basis. They don't always feel that I have the patience or I should always be going "Hi, sweetie. How you feel, sweetie?" Look, I work here seven days a week. When my daughters come to visit, they can do that (be very sweet to my mother) because they stay in the room 20 or 30 minutes and then take off. So sometimes it causes dissension between (my daughters and me) because they'll say something (about the way I talk to her) and I'll say, "Look." And my grandkids are the same way – they don't walk in and go to my mother first and kiss her first. And it just causes a lot of dissension, and my husband tries not to get in the middle. Sometimes he feels like my sister takes advantage, but I know that my sister can't make decisions...

Taking care of her mother disrupts Susanna's family life,

... We'll be at the table and before we used to offer to bring her to the table, but no, she wants to go in (to another room) and sit, and I said, "No, Ma, this is our family Sunday like we used to have." ... so I'd have to get up from the table and I'd have to close the door (to help her), and usually by that time, everybody's gone from the table...

Susanna recognizes that she has some issues with her mother,

My mother is very selfish. My dad put her on a pedestal and I can hear my dad still saying, "Susanna, please come over because your mother is raising hell because she hasn't seen the kids in two days," ... people have always catered to her because she's always been a little sick and a little dizzy, and she's one of those people that enjoys being sick, not as sick as she is now, but...(she would say),"Do you mind walking to the store and finding my wheelchair and my key, everybody comes to help me and you open the door, and you ask how I am." She feels that she wouldn't have that if she (wasn't sick), and this is... why people go to psychologists, but like I say, I do have a heart, and I do have adult mother/daughter conflicts. I have things, that when I was divorced and stuff, that she did, and I have angers and animosity, and you reverse roles – now you're the mother and you can tell her what to do. She can't tell you.

Susanna feels very constricted by the care for her mother and does not receive much family support or help,

I'm 58, I'm far from being too old, and my husband and I, we can't even go to the beach for lunch on Saturday without me getting a babysitter or having to tell my sister. Because I'm not comfortable with my sister the way she feels, I go and then and usually when I get home, my sister is in a bad mood and then I take it personally and then I'm pissed off at her, and I'm pissed off at me, and I'm pissed off at everybody... It's just overwhelming for her, so that's why sometimes on Monday when everybody leaves, it's like... I tell my sister to go take two days off because she causes more of a conflict because then I get aggravated with her and I'm aggravated with my mother.... You have no life. You really have no life.... like now, we're going to the beach for five days the week after next week. My husband has two weeks vacation, but this year my sister is so bad off that I don't feel like I can leave them for more than four or five days, and my daughter's here and she'll help, and my other daughter will come...

My sister feels very guilty, too. And she does very nice things for me, like she bought me that portrait that was on the back wall that I saw at a place one time, and she bought me some gold earrings and she'll always say "this is from Mom and me because you're the mother now, and I know I don't help you." And so I know that ...she just can't help how she is.

Susanna has had some problems with her mother over the years,

.... we did conflict, especially when I got divorced... We still do things that she thinks are terrible and horrible. We're living in different times. She's still in Italy when you went down the street and you went to one dance and everybody in the whole town was there, and you didn't worry about this or that and she's sees dad in everything – that's always been her. She would be a lot happier if she could be just positive on anything...

The emotional cost of caregiving is far more difficult than the physical requirements,

It's very difficult, I can handle it physically. Mentally, it's very hard. I had a TMJ problem. Last week I had a headache for four days... Sometimes, you just go to bed at night and cry, you think you haven't done nothing right all day, because she'll have been depressed. And her depression reacts on me different. See, everybody thinks I'm very strong and very hard, but I can handle everything and so therefore, it sort of always gets dumped on me. Not on purpose, but sometimes, you know I just can't (do it). You know, when she starts, not being mean, but when she starts feeling sorry for herself, you know, I'll say, "you know,

Ma, you need to not focus on what you don't have. Focus on what you do have." Sometimes at night, I'll say to my husband, "I don't think I did anything right today. I don't think I said anything right, I just want to go to bed and forget about it, today." But it's more mental stress than it is physical, even though I do have two ribs out of place because (of lifting my mother). They just sort of wobble... I can change her, I can bathe her, I can do it, but the mental, it's just ongoing. Last night, it was my son-in-law's birthday... My mother's used to being in the middle of everything that goes on with them and it's very hard for her to accept and not feel sorry that she can't be there. And she doesn't realize, or whether she does or not I don't know, I hope she doesn't, but, she likes to implement a little bit of guilt on you (for leaving her) as you walk out the door...

I don't want to say this to hurt her feelings. I have no life of my own. I have 2 grandchildren. I have 2 children. I can't participate in hardly anything they do anymore. Last night was my son-in-law's birthday. So I had to pay someone (to take care of my mother). We were at the restaurant 4 and a half hours by the time we were totally done, so that my sister could also go and my daughter could go, which is the family. Because when I go, my sister has to stay. Or when my sister goes on vacation, I have to make sure that I'm here the whole time. And like my granddaughters can help, but they're still really uncomfortable with the hygiene part (of my mother's care). You don't want your grandchildren to have to do that. You want them to remember and see their grandmother as a grandmother, not as a, you know...

You can't always be the caregiver and the love giver. It takes two people. It takes other people that can come that don't have to worry about what they're going to cook at five and six o'clock for everybody, someone who can sit down and have the time to give all the compassion. I'm the daughter, but I'm still like a worker. I know what I have to do every day and what I have to accomplish. I can't leave clothes for three days and say, "Oh, I'll sit with you today, Mom, and talk. We won't do clothes..."

I always tell people you cannot give the kind of things that you have to do. You can't clean shit and do urine, and do all the immodest things that you have to do. It takes something away when you look at that person, you no longer always see them as your mother. You see them as a person who you're taking care of. It's not like a baby that it's going to grow out of something. It's just going to get worse.

... I mentally can't give no more love. I don't have nothing left, except my grandkids and my kids and a lot of times I'm very short with them on the phone. They'll call and they'll say "What's wrong?" and I say "It's just a bad day – don't call me" and then they get a misunderstanding of things that are going on and they get hostile with me and so, it's just hard that way. But it's always people that are not as mentally demanding as my mother. I talk to other people that are, but of course they are a little more independent. They don't feel the hostility (from my

mother), I'm sure she has a lot of anger. I'm sure sometimes she could get the bedpan and throw it at my face.

Problems

A major problem for Mrs. Burris and her daughter is the lack of transportation.

The family lives in one county and her mother's long time doctor is in another county so they cannot transport her mother using a county van.

Susanna also has problems scheduling the hours for the agency worker,

... I have a girl now that comes, and she works for one of the health agencies and the only time she had available for me right now was a Wednesday, so I had to do everything on a Wednesday. But she had a client until 10, so she can't be here until 10:30. By 4:30, my husband and my sister were home, so I only use the agency worker six hours on that day. Well, I can't get anybody else to come for two hours, so what I do is I pay the worker for eight hours, and then she ends up owing me six or eight hours of work. Like last night, when we had to go to a birthday thing, she just comes in and we deduct two or three hours from what she owes me. I have to explain that to the workers, because they sign a sheet saying that they worked from this time to this time. And of course, they don't want to be doing something that they don't think is right. It just make it a little bit more complicated thing to have to finagle it around. In other words, if the program is going to give me thirty two hours in a month, why do they care how I use it? If I have an appointment that says you have to do an MRI on Monday, Tuesday we want you to come back for results, and Wednesday we want you to do this . . . why can't I use the three days if I need them like that? Why do I have to say, no, I used one on Monday, one on the next day and one on the next Monday?

Susanna also finds it difficult to keep track of her hours and thinks that the program would be difficult for her mother to manage on her own,

There's no way she could have done the paperwork that Consumer Directed Care wants done, like hire the person. If you're an elderly person like she is (it would be difficult). If you have someone who is receiving this program for different circumstances, but who needs the program and they have all their senses to be able to do it, maybe they could get on the phone and hire somebody. But, I mean they give you a booklet this thick! That was supposed to be for my mother, because she was the employer with the PIN number and everything. After I looked at the booklet, it was just keeping track of hours and actually making up hours. I put that I worked from eight to one, five days out of the week, because what am I going to put? My mother wakes up at 10 tomorrow, so I'm going to put ten, to eight or nine? It doesn't really matter, you know. But it makes you have to

put something down there... I think as far as the program that way, they expect way too much from the person that they say is the employer. My mother doesn't really know that she's my employer...

Susanna has several problems, but she does think that they have been addressed by the program,

I don't really think that even that much more respite care more would help me because I have to do the things (to care for my mother). It's just that there are problems... If I go on vacation and I have a girl come in one day, my sister usually works from 7:30 to 4:30. I can't get anybody here at 6:30 for her to be at work. I can't get agency workers to work past 4:30...

I would say if they could help people in our age groups (with more money), obviously (more) money would help a little bit... Health insurance for the person that has stopped working like me (is important). If I had not got married last year, I would have been without health insurance. That's horrible, because I mean I had a hysterectomy and it was \$25,000... My social security for the next eight years is going downhill, so that's going to affect me, but one of these days my mother will be dead, but I still have to exist after that.

Instead of being at my higher earning and being able to increase my social security, I'm at my lowest earnings from the time I started work almost... not only the money, but benefits (would help). They say, "Well it's a new program," but sometimes I think my husband and I – we have been going together over three years and there's a lot of reasons why we weren't going to get married because of the house I own with my sister, grandkids and kids. I always said "I don't want nobody else again telling me when I can see my grandkids. There'll be no stepfathers..., but I think maybe that we wouldn't even have still gotten married if it hadn't been that he knew I needed the insurance so bad, because he wasn't exactly quite ready. This is a big household for him to take in. It's hard. The only thing that made it easier is he came to Florida from West Virginia to take care of his father. ... he was on a ventilator and everything. He had black lung from coal mining, and that him and his ex-wife had taken care of four elderly people one time for over five years. So he is aware (of the situation) and he could handle it, but someone else could never handle this household. I was divorced twelve years and I said "I'll never remarry because no one can handle my household," because we have been taking care of my mother.

Whatever raise my mother gets in her social security, I guess they consider that a raise, because, see, that's another thing. If she actually gets a little bit more benefit you have to cut what the budget allows me... I think what I make is \$12,000 a year from this program. That's before taxes. I get \$240 every two weeks from this program. No insurance benefits, no 401K, nothing. I have zilch now.

Susanna has a positive relationship with her consultant, but she received conflicting information about how to use the cash allowance,

Actually I said that lady (who gave me incorrect information) was staying at the Washington conference, so I don't know if they were doing two different programs or something, and I just think the main thing would be in the program would be just for them to simplify their bookkeeping, and I understand why (it's complicated), but you always have to worry about the person who is going to commit fraud, and who is going to do it wrong and who is going to take advantage, but they make some of their things (too complicated).

Benefits of the Program

Mrs. Burris says that she likes the program because her daughter is with her.

Susanna feels that caring for her mother at home on the program is a better option than a nursing home,

No, the program is very helpful because, like I say, if I put her in a nursing home, to begin with you would have the guilt trip seven days a week. She would be calling us, she would be crying, she would want you to be there every day, like when she was in rehab. I would go one day, my sister went the next, I would go another day. But when she was in the hospital we were there 24 hours a day, even when she had nurses and stuff, and I said what am I paying the hospital for? But we'd come in at 9 o'clock and "somebody's trying to kill me and there's a black orderly, and he had to change my diaper." And she did not let any man change the diaper, so we had to tell the nursing home, and we said "I'm sorry, I don't know what to tell you and I know it is discriminating," but (the hospital staff told us that the orderlies are CCNA's and they are registered nurses and LPN's...) that's something that the nursing homes need to look at. They don't have male and female wards. They think it works fine, but my mother was terrorized, and it wasn't okay, but she did grow up in fear of a black man who would scare you and he came to your window and stuff. She's an old Italian and she said "I know he was there to rape me." I said, "Ma, who the hell wants to rape an 80 year old?" Then she'll listen to the news and they'll say somebody raped, you know, an 80 year old, and she focuses on every negative on the news.

The financial help is important to Susanna, and the program does help keep her mother out of the nursing home,

It gives you at least a little bit of something to work with... the biggest thing is she loves family and she likes to be around family and when she gets upset about

something, she'll just say, "Well, I'll just go to the nursing home." And you know, that doesn't solve anything, because, the last time she went to the nursing home, she was crying all night, calling us at two, three, four o'clock in the morning, saying, "Come get me." I said if you go in the nursing home this time, cause we have our little chats, you're not coming back out. I'm not changing everything again and bringing you home. And I said, "I'm not visiting you seven days a week," and I think that's the biggest thing. At home she sees us seven days a week, whether it be an hour, or going in and out for food. And at the nursing home, you can't have a job for forty hours a week and go and get off at five and go to the nursing home until nine and then on Saturday go the nursing home and spend from twelve to seven o'clock at the nursing home.

I really think that if she had been at the nursing home, she would have already been dead. Not because of their care, (but) because, ... even when she was there the last time, there was like no point. What's the point of doing anything? My family will only come one hour and there is no point in living.

Susanna likes the Consumer Directed Care program,

I think if they have a mother that they want to take care of, then yes, the program really is a help, and like I said, \$430 still pays the bills, you know. Just like people that say I can't go to work for \$15, unless I make \$15 an hour, when I got divorced, I worked with two kids and made \$5 an hour 'till I could get back up, you know, and yes, it does help and if I wouldn't have been getting any of that and been home it would have been twice as stressful because I would have had to figure out some way of working at home, too, and I even still don't have that option because I can be on the computer twenty minutes doing something and I'll have to turn it off, stop and come over here. So there's nothing that you can do continuous – and I even thought about, well I could take care of, you know, little kids. I said, "Are you kidding?" I'd go bananas!

I tell people I still would rather be home now with her than having to go back to work at this stage of everything. I enjoy my home and that's one of the biggest pluses. I enjoy my yard, I can stay in this house, and I call it "play" all day long. I'm a junk collector, my biggest thing is to go to Goodwill or the thrift stores and stuff... And because I love being home, that helps a lot with the resentment of me not feeling like I have (a life), because I do enjoy being home, even if the home is what I have to do.

Like I said, I'm very appreciative of the program. I think for a person who has made up their mind that they are going to stay home and take care of their mother, that it is a help unless you're, you know, a doctor's wife already, and you can afford them to have a regular RN come in, take care of a home, and still...yeah, obviously the ideal thing would be to keep her home and be able to have a 24 hour RN or LPN come in. Someone who (inaudible) and then you could give the love and support that they want.

You Can Always Get Somebody on the Phone

Susanna is satisfied with her consultant and with how Consumer Directed Care is administered.

Our consultant came for two days. She showed me the time sheets and we went through everything and she's really been great. You can always get somebody on the phone, they always have an answer for you, they're great. She has given me her home phone and her cell phone, and her car phone. So she says, "Don't give this number out." But she has always been super with me...

Consumer Story 3

Mr. Bruce Newman is an 81 year-old white male who was diagnosed with Alzheimer's disease 7 years ago and is now in Stage IV of the disease. He is a widower and has lived with his son Roger and daughter-in-law Candace for twenty years when he first suffered a stroke. The family lives together in a small suburban home near Tampa. Roger acts as his father's representative and Candace is the family caregiver, although they both provide care to Mr. Newman. At the time of the interview, Florida was experiencing a heat wave. Since their air conditioning was broken, Roger put his father into a nursing home for several days until they could get the unit fixed. Mr. Newman was unable to participate in an interview, so Roger answered the questions as his representative. The interviewers were not able to contact Mr. Newman's consultant.

Medical Condition

Even though Mr. Newman was diagnosed with Alzheimer's 7 years ago, Candace says that she and her husband noticed symptoms three years before that. Roger describes his father's behavior as increasingly aggressive and "... all combative and not controlled with his mouth...., yelling, screaming, cursing, or throwing things." Roger says that his four children visit or bring friends to the house and just accept the behavior and never complain about it.

Enrollment in the CDC Program and Previous Experience

Roger and Candace first heard about the Consumer Directed Care Program when they received a letter from the program office. They called and their consultant came to their home to answer questions about the new program (which she also helped coordinate) and they have been enrolled ever since.

They wanted to enroll in the CDC program because they were unhappy with the agency and agency workers they were using. Roger says that the workers were unreliable and did a poor job caring for his father when they did come to work,

We weren't happy with the service that we were getting. The reason that we weren't happy is because somebody was supposed to be here, I would make arrangements for me to see the doctor or... so that I could get away because I was here for 24-7. Unfortunately, the agency said, "Our girl will be there on a Tuesday at 2:00." Okay, I will make my arrangements. "Oh, we can't get there today. We won't be there at 2:00. We will be there at 6:00." That was a constant thing going on and on and on. It went on for years. The agency would say, "Well, you have to understand that we have other clients, and things happen." Well, sure, but if so, then don't say it's respite (care).

When they were here, the care was terrible, absolutely terrible. They (agency workers) would come here and bathe him and leave a mess in the bathroom, so I would have to clean the bathroom. Then he would take a b.m. and he would make a mess, and I would have to clean that up anyway. So I was doing the work anyway. It's that simple. I was doing the same work, and why should I? For 19 years it has been that way.

According to Roger, "This situation is better than the one I had. It was not reliable. It was not compassionate. It was not redemptful." When Roger depended on agency workers for his father's care he, "... agonized. Worried every day when they were supposed to show up... It wasn't a pretty sight." Candace concurs and feels that the worst part of agency care was that you could not predict when a worker would come to work.

Hands On Care

Mr. Newman needs extensive care. Roger describes what he does for his father,

Give him his meds. He can't take that by himself. Wash him. Shower him. Feed him. He can't feed himself. You literally have to feed him. Put the TV on; for conversation. Feed him his meals. Put him in his wheelchair; you know. It's hands on.

Roger changes his father's clothes and diapers. Candace explains, "Hubby changes his clothes because he is a male and no matter how old he is, it's still his dignity." Both Roger and Candace share equally in Mr. Newman's care. According to Roger, the most difficult task is showering his father. Roger feels that he and his wife take better care of his father than an agency worker because they know him well and can anticipate his moods. As Roger explains it, "I can look in his eye and know what is going to come." Roger feels that the most important thing he does for his father is to protect him.

A Seven Day a Week Job

Roger spends his day at home and Candace spends all her time before and after work taking care of Mr. Newman. Roger says that the hourly caregiving pay is "... just paperwork. It has nothing to do with physically what is entailed (in the care of his father)." Roger describes a typical day caring for his father,

(A typical day) would look like getting up in the morning, feeding him, giving him his medication because he has to have the meds all of the time at the same time... I'm a very regimented person. If you have it at 6:30 in the morning and 1:00 in the afternoon, and 6:00 at night, that's what you do. That's the morning. We feed him and wash him. You got to keep him clean. You got to watch out for bed sores. We brush his teeth, which is very difficult to do with Alzheimer's patients because he bites the brush and does stuff like that. We put the TV on. He uses pads so I have to change him, and do laundry, which is not an easy thing for a son to do for a father. It took a lot of adjusting; I have done that in the shower because it is like having a grown kid. I idolized my father all of my life, and it is very upsetting washing his bottom. It's a different ballgame. It's just a commitment. You make the commitment or you don't make the commitment. You can't do it half way.

Candace gets paid for 20 hours a week of care, 4 hours 5 days a week. Candace gives her father-in-law breakfast in the morning and then after she returns from work,

I give him his dinner. I go in there and I talk to him. We sit and we try to have a conversation. I put the TV on for him. I put music on for him. We try to include him in things, but with the Alzheimer's, it is very hard now. There is not much. He is clueless to what we are doing or saying.

Candace and Roger try to include Mr. Newman in family gatherings, dinner, or trips to the mall, "... but that's getting harder because he is not understanding and he doesn't know where he is. He gets very disoriented." Roger and Candace decide together about what needs to be done for Mr. Newman.

It Has Nothing To Do With Money

Roger thinks that if his father were in a nursing home it would cost the state 4 to 5 thousand dollars a month for his care. The money Candace is paid for caregiving does not cover all the care needed by his father,

(We get) about \$749.00 per month, 6.50 an hour. You know, it has nothing to do with money. It can't have. It's impossible, because if you figure out what my father needs it's not enough. I could take you and show you the stuff that you have to buy... They don't pay for medications, no meds, no doctors.... You can't be doing this for compensation; it's got to be for love. If I was getting \$50,000 a year it would be compensation; if I was getting \$20,000 it would be compensation, but for what they pay you (it isn't for the money)... (We use the money) for personal care items, every penny goes out.

Candace also states that their caregiving is not about the money,

There is never enough. There is no compensation in the world that could pay you for what you do with a family member. There isn't. I mean, this is a choice that we made to do, and we have been doing it before this program even came into existence, so it has nothing to do with money. You've got to be able to do it and make these sacrifices and be there and understand this person because Alzheimer's is very, very hard.

Very Few People Understand Alzheimer's

According to Roger, it would be impossible to hire someone as a caregiver for his father because even nurses and doctors do not know how to care for someone with Alzheimer's. For Roger and Candace, family caregivers are the best option. Roger says that, "nobody knows and nobody cares like a family." Roger feels that his father knows when he has a strange caregiver,

He doesn't have to say the words. You can look at his eyes and know. He gets irritated if it is somebody that he doesn't know. He is going to let me do what I want to do. All the other people he fought. They (Alzheimer's patients) need the same routine because anything could throw them off, anything. I could change the channel on the TV, and he will notice a difference. He could fly off the handle...

Candace describes the important qualities of a caregiver,

You have to have compassion, understanding, patience, and you have to love the person. If you don't have those things, you can't do it. It would be hard (for someone outside the family to provide care for her father-in-law). I'm not going to lie because I mean it's your dad... You have to be able to change their diapers. Listen to the combativeness and understand that it is not the person. I would be more than willing to show somebody what to do, but to take in a stranger (as a caregiver), no. No. I'm sorry, no. It's has to be somebody that you know and you love and you don't mind making sacrifices for, and after making these sacrifices and stuff like that, I don't think in my heart, I don't think I could do it for a stranger.

Candace has known her father-in-law for 41 years and is willing to care for him because she loves him and does not want to see him in a home,

I love it. I love him being here. I couldn't see putting him in a home. We had him for so many years.... He (Mr. Newman) doesn't understand (what is happening to him), which is good for him. Knowing the man that he was, if he knew what he was going through now, he could never understand it. He wouldn't believe that it was him.

Candace feels that their caregiving has brought she and her husband closer together,

It's just that we are very lucky, my husband and I, that we can do it and we understand and there is always one or the other there to do it. (The caregiving) takes time away from us sometimes and we are just too tired, but it made us closer. In the beginning, we would argue because I get frustrated and he gets frustrated, but then we realize, what are we arguing over? The poor man doesn't have a clue. We looked at each other and we laughed and we said (this is) stupid, and that was years ago.

Candace explains that she and her husband only rarely ask their children for help in caring for Mr. Newman, "... remember they have their own lives, too. I love my kids, but we took on this responsibility, not them..."

Caregiving Experience

Roger has stayed home with his father for 19 years since he first suffered a stroke and has always cared for him. Candace describes how they learned to care for Mr. Newman by doing what he needed. When Roger and Candace began to notice their father's erratic behavior they talked to his doctor and community agencies to try and find out what was going on and were told that he probably had hardening of the arteries. According to Candace, it took two years for his Alzheimer's to be diagnosed,

We kept saying, "This man does not have hardening of the arteries, I'm sorry. We know what this man is having. We have read and we have gone to the library. Following the way it goes, there are different stages. I mean, somebody listen to us" until finally they (the doctors) did. The doctor did the stupid Alzheimer's test and he flunked it like that. My opinion is now they have these experimental groups and stuff like that, but my father-in-law is too far gone for that. Years ago, there was no help. There really wasn't, which was really sad. Now there is more help out there, but unfortunately, it is too late for us.

Problems with the Consumer Directed Care Program

Roger and Candace both feel that one of the drawbacks to the program is that they receive very little money every month for the care that they provide Mr. Newman. Roger thinks that since agency workers or a nursing home would receive much more money, he and his wife should get more than pay for four hours a day. Also, since Roger and Candace provide all the care themselves they have no one else coming to the house so they never receive respite care. Candace explains,

I really think in my heart that we should get more. Maybe then we could be able to do more. You do give up your life.... My husband and I cannot go out together and go to family functions or just go for a walk on the beach.

Roger and Candace occasionally have problems with their check getting lost in the mail, but in general, do not find the paperwork to be a problem. Roger says that if they ever have a problem they call their consultant who helps them solve it.

It's a Good Program

Roger feels that one of the benefits of the program is that he and Candace could use their money to hire a respite worker if they had to, although he doesn't think that they receive enough every month to make this practical. Roger says that he has more control over his father's well-being by participating in the program,

I think the program is good because it came at a time in my life when I probably had to make a decision of what I was going to do with my father, and I was gearing up to put him into a nursing home because we were on our last leg, and at least it gave me an option to try something. I didn't have any options. The program gave me a choice; whether it was the right one I made or not, only God will tell me.

Candace feels that it is a good learning experience and that others may be able to learn from them and what they do in caring for Mr. Newman. She is very happy with the program.

Consumer Story 4

Pamela Morris is a 52 year-old white woman with multiple physical disabilities including multiple sclerosis, osteoporosis, bleeding from the colon, and vestibular ocular reflex (crossed eyes). Her multiple sclerosis and osteoporosis are rapidly worsening although she continues to be upbeat and cheerful. Mrs. Morris is divorced and lives with her daughter in a clean, well-organized apartment in an apartment complex with multiple buildings and floors in the Tampa, St. Pete area. Mrs. Morris has a walker which she uses at home and a scooter and wheelchair which she often uses to go “out in public.” She pointed out that she needed help cleaning the house and in performing any activities below waist level. She mentioned that she had fallen when trying to do things by herself. Mrs. Morris was dressed well in a nice outfit with her hair done and make-up applied. She was very cheerful, patient, talkative and friendly during the interview, smiling often and talking easily. Mrs. Morris has a young adult son and daughter who stay with her sometimes in between apartments. Her nineteen year old daughter Kathy is her caregiver. Both she and her daughter mentioned that Kathy would be moving out to live with a friend who also sometimes helps Mrs. Morris by running errands. Mrs. Morris was sad that her daughter was moving, but Kathy will continue to be her caregiver.

Medical Problems

Ms. Morris has some serious physical problems as the result of her Multiple Sclerosis. She describes her medical condition,

Well, the reason I’m on (the Program), I had Multiple Sclerosis. Initially 25 years ago it was very mild, but it progressed through the years and now I guess it’s what they call ‘secondary progressive’. So mostly it affects my lower legs, my speech a little, my organs, just like that. I was going along pretty well. I was a stay at home Mom until 1990 and then quite a bit of things happened. My parents passed away, my ex kind of became a, ‘dead beat Dad’ and all of that good stuff so the

children and I were forced into a bunch of different circumstances. I tried to complete my education at college ... , but I had problem with my optic nerve. So that happened and so all of a sudden I went on SSI. Work history over ten years old, no insurance, no funds, ...and basically was forced onto SSI. I had enough work history credits, so it's kind of been a rough road for the last 12 years or so, but that's basically my story.

I'm concerned about my health. It (the MS) is advancing – it's moved into some kind of progressive stage, whether it's secondary, or not, my doctor says primary. I am in denial. I think it's secondary, but anyway I try to stay afloat on a walker but only around the home and then a scooter or wheel chair out in public. (With) Florida's heat I'm basically holed up in the house.

Mrs. Morris also describes a problem she has when her blood pressure drops precipitously,

I have something called vaso-vagal – if I try to work too hard, my daughter can tell you, my blood pressure drops suddenly and I pass out, real bad, and she took me to the hospital one time I was banged up, but the next time it happened I called the paramedics and said, ' I'm having a vaso-vagal, the blood pressure is dropping fast. I have a little dog, the doors open, could you come real quick.' They are right around the corner. I said, 'Come quick, or I'm going to pass out and no one is here.' So they came and they wanted to take me right to the hospital because the blood pressure was like 60 over 20 and I said, 'Don't worry, don't worry, just lay me out flat on the bed,' and in two minutes it was back to normal, or relatively normal.

Mrs. Morris describes that she also suffers from osteoporosis, depression, and eye problems,

I had one manic attack after taking 80 milligrams of Prozac. I had what was diagnosed as Dysfinia, that's a low grade depression and so I was treated after I lost my sight and my chance at Masters Degree and all that stuff, and losing the house, and driving, the pool and kids and all that supported the ex...I got quite stressed, so they just gradually increased the Prozac. Once I no longer was able to see a good psychiatrist, I had to go to a GP. So, this doctor I had currently, he is through the state, said it (her manic attack) could have been pharmaceutically induced, but I don't know. So they diagnosed Manic Depression. I took an old medicine for it that made me too groggy. I'm on one now that they think might help if you do have that condition, but it's also an anti-seizure drug which helps because I have a spasticity problem. So it's been much better. I'm with an eye doctor now... I have a couple different things. O.K., let me get this right, the crossing of the eyes is the vestibulo ocular reflex. That's this dragging of the eye not going left and right. You feel dizzy or nauseous and it's

why I tend to fall. I can't move my head suddenly, that's why I have to go to the walker. And it's in the optic nerve now – it's in the optic nerve – and the doctor told me the cornea is now affected because of all the Prednisone that I used in the last 25 years. Yea, that's how I got Osteoporosis, from the Prednisone.

Kathy describes how her mother's condition has worsened,

She's had MS for over 20 years or something, but she just got bad over the past like eight years, where she's had to move from a cane to a walker, and the walker to a wheelchair now, and she's getting worse and worse slowly through time.

Entering the Program Flows from Previous Arrangements

Mrs. Morris was very excited about what the Consumer Directed Care Program would allow her to do. She was approached to enroll in the program through the agency where she had been receiving services. Her consultant for the CDC Program is housed there. She had received homemaking and counseling services and equipment from this agency before her enrollment in the CDC. Mrs. Morris' consultant said that she was one of the earliest consumers to enroll in the program and needed a lot of attention at the beginning because she had non-traditional needs.

Mrs. Morris believes that her enrollment is a benefit to the state. "I know I'm costing them almost half, or less than half the amount (of traditional agency services) whatever it is, but I get more (services) so that's wonderful." In the 9 years that Mrs. Morris received traditional services from the agency, she did not always have a good experience with employees,

"Oh, and the choice of employees! I got some bum employees. In the 9 years with the agency, (there were) maybe only 3 exceptional people that I would say they are doing their job. All the rest were either not up to the task or had real weird personalities. There was a young girl, a retarded girl, she tried, (but) you know you have to hire high functioning people. So anyway, I was kind, (but) I just knew that... I had to get a new (worker).

How Do You Determine Need?

Mrs. Morris needs quite a bit of help as a result of her physical condition. At the same time, she tries to do as much as possible by herself and is not always sure what determines need for a service. She says that the consultant always asks, “Do you need personal care? Can you get out of your bed?” Mrs. Morris comments,

And, yes I can, but I pull up on the walker and then I grab the dresser and then I grab two grab bars, so it’s like, well I can, and I can get my pants on, it’s quite hard, but you lift up one leg. So I thought, well, I can’t really justify personal care yet, but when do they determine it is a need?

Mrs. Morris needs someone to be around to help her in case she falls,

... the only thing I’m worried about is if I fall, which I’m starting to do about twice this month. Once I got up on my own, once Kathy was around to help me. Oh, and a third time, my son got me up. (I fell because I) try to do things I can’t do and it’s a good thing my family were around.

Mrs. Morris needs help with many different tasks,

I can’t stand to cook, so at this point I don’t have enough hours and my daughter isn’t a cook unfortunately. So I’m Slim Fast. I use a salad and a Healthy Choice dinner every night. Mary (a friend of her daughter’s who runs errands for her) is my shopper. Kathy gives me my shot. I can’t stand it, we’re suppose to self inject, but she is going into nursing school so she just takes that one inch needle and says ‘Mamma, don’t look, do your Lamaze breathing.’ She pops it right in. Getting shots and getting off the floor, these are the real crisis things. (I need) just a lot of cleaning. I can’t do anything below my waist, really. I try to, and when I do that’s when I fall. Or, if I move my head suddenly left to right, because of my eye troubles, I’ll fall.

Kathy describes what she does for her mother,

All kinds of cleaning chores, vacuuming, mopping, cleaning her bathroom, anything you could think of cleaning, really. I give her shots, which she gets once a week. I do her laundry and stuff like that, cook for her.

Schedule and Pay

Mrs. Morris pays her daughter for 3 hours of help each week at \$7.25 an hour.

Kathy sets her own hours. Kathy describes her schedule, “Usually I just plan for that

week. Every day I have off from my other job I stay home and work for her. And sometimes I can do it after work.” Kathy says that she “sometimes, but not all the time” works more than three hours a week for her mother.

Supervision

Kathy says that her mother decides what needs to be done and supervises her work,

She just writes me a list of what has to be done. She double-checks everything to make sure it is all done right. She keeps an eye on things.... It’s a good thing for her, too, to have this and to run this, it makes her feel like she’s doing something, and she’s really enjoyed it so far. I think she really is (enjoying being in charge of her own care) because she’s a very strong-headed kind of person, so I think she’s enjoying it. I think she’s happy doing it, and cleaning everything out and doing the book thing (taking care of the details).

The Most Wonderful Relationship

Mrs. Morris feels that it is a “little tough” to supervise a family member, but she gets along very well with her daughter Kathy,

I’m dreading her moving, because she just turned 18. We have the most wonderful relationship and at 18 she is moving out on me. But she is a good girl, she gets her work done and then...I mean, bring me this, bring me that. She has picked me up twice, in the last month...

Kathy describes her relationship with her mother,

Pretty good. Because I’m moving out and getting older, you know how moms and daughters get, but it’s good. I think it’ll be fun to have a chance to come here once a week to do the work for her and spend some time with her. That’ll be nice.

Kathy mentions concerns about her mother when she is not there, “Just if she’ll be okay when I’m not here, she’ll fall or something like that, because she’ll fall every now and then and need help up, those are concerns.

The consultant says that there were some problems in the beginning with Kathy because she was not very reliable because, “...now we’re talking teenage daughters.”

Being Fussy

Mrs. Morris feels that she needs a caregiver who will work with her “fussiness,”

... not just somebody that will come in and say, ‘O.K. we’re going to take out the trash, vacuum, dust.’ You know there may not be the need for dusting, or this or that one week and I might say, ‘no help me with this (instead).’

Mrs. Morris adds that she would like someone who is very patient and likes to listen because she is very talkative. The best kind of caregiver,

I think would be an older person where our personalities matched, but Kathy is so effective, but that’s because she really needs the money and she... goes above and beyond board in all the little things she does throughout the week, but we just have a mother-daughter, ‘I gotta, move out (relationship).’ She thinks it will be a lot better, because she is only like a quarter of a mile away (in her new apartment). When she comes over she won’t have a bed to nap on, ‘Mom I’ll do an hour now and two hours later.’ But I write lists for both caregivers, they all get lists, and she completed her list.

And poor thing she is working that way at Pier One... and they work her to death so when she comes home it’s like ohhhhh, but see it’s hard to find them (caregivers). You can find cleaning services. I have friends but you don’t want to compromise work and friendship. That can get a little hairy.

Mrs. Morris knows that she has to be flexible to get the caregiving she needs, “Of course these girls are going on to nursing training or college, but they both are going to work as much as they can. So, I’ll have to work around their schedules....”

Kathy enjoys caregiving and thinks that it requires patience,

... ever since I was little I just knew I wanted to take care of people. I wasn’t sure if I wanted to go into childcare or adults, like nursing. But then I just decided I’d rather do nursing, and taking care of mom with her sickness, and kind of helped to take care of my grandparents while they were dying, so it’s just kind of in me, you know. I grew up around it, so I enjoy it.

Relying on her Daughter’s Friends

Mrs. Morris gets support from friends and her church, but she cannot rely on them for care, “... Kathy’s friends help me more because she doesn’t have a car and they

come and go and they will stop and get a gallon of milk for me, or this or that. Mrs. Morris says that this help will end when her daughter moves out.

Using the Cash Allowance

Mrs. Morris is very aware of the way in which the Consumer Directed Care program allows her to save the state money. She receives \$415 a month. She uses the cash allowance for 6 hours a week of caregiving and for personal hygiene supplies and assistive equipment.

...But the best thing is it allows me about \$105 plus change in monies in buying the products I need, which (the agency) had provided (before) but were much more costly to them and I can get them much more reasonably, plus I also have Osteoporosis and a bunch of other little stray illnesses that come along. So I can get over the counter meds that I couldn't before and Kleenex, Cottonell wipes, real essential stuff ...

The cash is the best thing about the program. I (also) have to save towards my own equipment instead of like just coming up with the needs I have as I worsen... I have needed new batteries, (for) the scooter...I was in need of a better walker so that kind of left me in a pinch for awhile, but my savings are catching up... If your health worsens dramatically, lets say I need in-home care for personal hygiene, Kathy helps me sometimes, she gives me my shots, my Avinex shots but mainly she is the one that takes care of me. She does all my housekeeping and things the way I need them done. I have another housekeeper who runs my errands. I only travel by wheelchair transport so that way, she goes wherever I need for her to go and you know, be it the Post Office, or drug stores or grocery stores. So that works out well.

If Mrs. Morris needs new equipment she has to re-do her purchasing plan. She feels that she needs a Medic Alert system, "...but that's so much a month and there is not room in my budget to do it." Mrs. Morris describes some of the things she buys with her cash allowance,

Oh, (I need) a lot of things. With the Osteoporosis I take the calcium with Vitamin D, I have to take a regular vitamin, the Century Senior. My doctor wants me on something called Glucosamine Chondroitin – it has so many milligrams.

I need a lot of paper products. My bladder becomes incontinent and I'm bleeding right now from the rectum. They repaired it once already. I've seen a specialist, they can't repair it again, so it's (maybe) a colostomy. I have to make the choice and investigate that now, so with (the bleeding) comes the need for wipes, extra toilet paper. I get those Lysol wipes because I'm always messing the toilet and you know I can't clean it every time so (I get) those kind of incontinent products.

And oh, I get more homemaking hours (than I did at first). I only got three on the old budget now I get six (hours a week of caregiving). And the final thing is oral care products because my gums are totally going away because I'm on so many medications. So that's what I'm able to get with cash. Save for equipment I need, and that can be all kinds of stuff. Oh, see, I've already gotten most of it – battery charger and scooter, elbow and wrists supports, the walker – I haven't gotten little things like support hosiery and ankle supports.

Mrs. Morris's consultant describes her cash plan,

She was one of these earlier people to go on (the Florida program)... She had different things that she wanted to obtain that were really not traditional services. Her purchase plan was very elaborate and it actually got out of hand. It was way too confusing (so) we simplified her purchase plan. After that, it became a little easier for her. They (the fiscal intermediary) had some difficulties with the accounting and all that, the statements in the earlier periods, until they got things straight.

It Helps to Have a Professional Counselor

The consultant helped Mrs. Morris fill out the paperwork for the Consumer Directed Care Program. Mrs. Morris describes what she appreciates about her consultant,

He is accessible by phone, he gets right back if I have one of these crises with the (fiscal intermediary) (like them) not getting back or fouling up, mixing me up with another person. He just gets right on it and unfortunately the state laid it in his lap to figure out how to budget my account so I'm sure that was a great additional amount of work, but he is just so professional, patient. When I first started, and I said, 'I need a walker' and I feel like going back with my original agency... he said, 'Just hang in, hang in, they're working out the bugs.' He is marvelous.

Problems with the Program

Mrs. Morris identified difficulties with the accounting system in the program as the biggest problem,

That is the worst part of the program. Some of the ladies (from the accounting firm) try very hard to answer your questions and they went through a big computer change around the end of 2001, but there are just so many mistakes now. Like now that we can blame (the delays) on the Anthrax but for a long time people just didn't know what money they had or their response from the people up there. The personnel were not timely, or they might not get back to you. You know they had to research it quite a bit so then, and of course I got into a brouhaha with them once, which ended up being my fault, but most of the time it has been their fault or their computers. I don't want to slam the employees, it's gotten better, but the last two checks, my two employee checks and my cash check for the month, were mis-dated. My daughter Kathy is trying to qualify for an apartment and the apartment people called and said their corporate office would not accept the stubs (her pay stubs) because one was over-lapped. In other words, the pay period went from 6/30 to 6/30, that doesn't work. So there are a lot of mistakes there. Oh, and they mixed me up with another client. There is evidently another Morris in Florida. So they told me I had enough funds to get the walker and I thought, have I saved that much? I wasn't real sure, but two people were telling me that I had the money, but I really didn't. So now my poor consultant is trying to figure out how to balance all my funds, because I'm really in the negative. So that's my complaint. I'm sure the fiscal intermediary company is doing the best job they can with the money they are paid, but it's just really taking a while to iron out all the bugs.

Kathy agrees with her mother about the problems with the program,

The problems would be with the payroll. Also, like the checks being dated wrong or something, 'cause with my apartment I've had to bring in the pay stubs. And they were dated wrong or something, and so she had to clear that up and all, so it was kind of a bummer that's pushed back the apartment a little bit, but no big deal, and the checks usually aren't on time. I'm usually waiting a little extra for them to come, but other than that, nothing.

The consultant said that Mrs. Morris' budget is overspent, "... but it wasn't really even her fault because they had made some major, major errors in the accounting." The consultant said that at the beginning of the program they did not get a monthly budget report so it was impossible to monitor a person's spending in the program.

Benefits of the Program; You Get More Bang for Your Buck

Mrs. Morris likes the flexibility of the program and the cash allowance she can use for her non-traditional needs. She also feels that she can buy supplies more cheaply with her cash allowance,

Having the personal consultant is wonderful. I know I'm costing the agency less than half the amount (it cost to buy supplies before the program), but I get more so that's wonderful... I never could have afforded to go to pool therapy on my own. It's all I can do to get to my doctor's appointments. You get so much more bang for your buck. You get more for the money as far as product goods, and hours of service.

Mrs. Morris also likes the fact that she is able to choose her employees. Her experience with agency employees has not been good.

Kathy describes what she likes about the program,

Let's see, getting paid, right? (I like) just the fact that it is more scheduled and actually not like asking me to do favors here and there, all over the place. It's just kind of set, you know. She tells me when to do the list and what needs to be done, and then it's done for the week. It's not kind of scattered, the extra things here and there.... It's a nice side job, too. I don't know if people do it full-time, too, but for me it's a nice side job in someone's house, not to go through so much trouble, and I like everything about the program.... I think it's real interesting how I can be hired to work for her and stuff, and I think it's fun.

The consultant does less for the consumer directed participants,

I don't really have to hear from the CDC people that often because they are operating their own services. They are the bosses. They are their own people. With consumer-directed care, they are the ones that have to put together the program. If the aide doesn't show up, they have their back-up and there really isn't any need to be calling me because it's their employee.

Consumer Story 5

Mrs. Regina Erdman is a 55 year-old white woman who lives with her husband, Gil, and adult son Ron, who is also her careworker. Mrs. Erdman has Osteoporosis, Chronic Obstructive Pulmonary Disease (COPD) and Emphysema. The Erdman's live in a small apartment in an economically depressed suburb of Tampa. The apartment consists of a small kitchenette and combined living room and dining room area and two bedrooms. The inside of the apartment was unclean and cluttered. The wall to wall shag carpeting appeared dirty and the odor of cigarette smoke and alcohol was strong. Mrs. Erdman was interviewed while sitting up in a hospital bed in a small bedroom. She was wearing pajamas and her hair was uncombed. The bedroom was quite dark because the light hurts her eyes. In addition to the hospital bed, the bedroom held a small television on a dresser, a nightstand, and a couch. The nightstand next to the bed held an ashtray, cigarettes, and a large tumbler. Two small dogs ran in and out of the room during the interview.

Health Issues

Mrs. Erdman has several serious conditions,

My major problem is Prednisone-induced osteoporosis. I've got probably 30 fractures in my spine and my ribs. Almost every rib on my left side has been fractured at least two or three times, almost every rib. I've got fractures in my right side and I have two compression fractures on the left wrist, and they hurt like heck all of the time. I wear a patch 75 mg., the Durigesic pain patch, and the doctor said that he would give me the 100 mg. patch, but I have emphysema also, so you know I have to be careful because if I take too much of something, it could really stop my breathing. I get real short of breath, and then I have the heart condition..., but they can't do anything about it. Ron, what is it called again? My pulse goes crazy. I ain't never heard of it, but when I noticed it, I got real weak. First I noticed my heart beating real funny. I got real weak, real nauseated. I mean really weak. The doctor said, "You need to see a cardiologist," so I went, and the cardiologist said that I have a mild leakage in my mitral valve... He said to take my beta blocker, (my irregular heartbeat) comes and goes at will. You

know, I will be fine for a couple of weeks and then all of a sudden, you know, for no reason this happens, and it can last anywhere from an hour to three hours. I feel really miserable with it. I think I'm going to die it's so bad, and then it just goes away almost as quickly as it started. And then I have emphysema, COPD, which has gotten a lot worse, so those are the three major things. Right now I would say it is probably my bones (that are the biggest problem). The osteoporosis hurts the worse.

Mrs. Erdman wears a pain patch, but has problems with the side effects,

It makes me groggy and some days I will be wide awake and then all of a sudden I get really sleepy. It's like somebody gave you a shot or something. There's no way that you can stay awake. You have to sleep... it takes me a good 1-1/2 hours to really wake up. To even talk to you. I feel so drugged, but the rest of the time I feel normal. The patch works weird. It will ease my pain for a couple three weeks down to maybe a level 2 and then I go for about that long and it will be a 7, or 8, or 9. It's not the pain; the patch is not consistent at all for pain, but like the doctor says, not too long ago I was complaining about how much I was hurting that month when I saw him and he said, "Well, just think about if you wasn't wearing it (the patch) at all, how you would feel?" He said you would be beat. I said, "That's right. I remember those days."

Mrs. Erdman must use a wheelchair when she is transported to the doctors by van.

She has been confined to bed for approximately 6 to 7 years at the time of the interview.

In the last five years she has rarely left the house except to go to the doctors because she cannot sit up for very long. She also finds it painful to sit on the couch or a chair because her tail bone and spine hurt.

Enrolling in Consumer Directed Care

Mrs. Erdman described how she first heard about the program,

Someone called me about six or seven years ago. See I've been in bed since (then)...Maybe it was probably 1996 from Maryland and they told me that there was five states who were going to participate in this (Cash and Counseling) program in the future and they wanted to do a phone interview. It did take an hour. At the time I didn't want to (enroll) because I had a good thing going. I had people who came in the afternoon, good people, but about two years later it started going downhill.

She began to have problems with unreliable workers and she heard that other adults with disabilities had these same problems. Mrs. Erdman then became interested in enrolling in Consumer Directed Care the next time she heard about it, when it first started in Florida.

Previous Agency Experience

Mrs. Erdman could not get reliable workers from her agency,

They don't have enough workers for the client. They keep taking clients. They have nobody to send out to them; all kinds of crap. They give you a time, like with me, I was told by three places, everybody wants morning. I wanted afternoon for a very simple reason. I don't feel good in the morning. My pain is worse when I get up. I take my medicine. And so any time after about around 1:00 p.m. (is O.K.).

I had two agency workers. I had one that came out for homemaking and one that came out for personal care, and I was supposed to have (received services for) seven days, but they couldn't care for me on the weekend, so it was five days a week. About three years ago I called up the agency and I asked them if I could go down (reduce service) to three days a week because I was getting worse and I wasn't able to get a bath every day. I didn't want a bath every day because I was either in too much pain or too tired or too sleepy from the patch or something... So, it's been about the last 2-1/2 years that I have gone to three days a week.

Of the three agencies she used since she started receiving services, two agencies were good and one agency was particularly bad and "shouldn't even be in business." Mrs. Erdman says that she had "very ignorant and silly people" as careworkers, in the two years before she started in the program, who would often call and cancel or just not come to work. Workers often changed their work times arriving at 11 a.m. when Mrs. Erdman expected them at 1 p.m., for example. One agency worker called several times a night before her work the next day to change the schedule. An agency supervisor came several times to help Mrs. Erdman in the shower because of the worker shortage. Sometimes, the agency workers did not seem to be competent. Mrs. Erdman described the conversation she had with Lisa, an agency careworker,

I had this one lady that came, the last one that I had, she was bragging. I was sitting over there while she was making my bed, and she said she couldn't make the bed worth a crap. I mean, she said "I don't make beds at home. I don't know how to make beds." I laughed and I was teasing, you know, I said that was obvious. I meant it, but she thought I was kidding, and I wasn't, and she said, "Would you believe I took the test to become a certified nurse (C.N.A.)" and she said, "I faked it. I never had any training at all," but since then I know that other people has done that. She didn't have any training or tests or anything.

Mrs. Erdman describes one agency worker who was very needy,

She needed to be needed. She is in the business because she always talked about how much her patients loved her and how they cared about her and stuff, and boy she was starved for affection. I liked her. I felt sorry for her more than I liked her, but she was the dumbest one I've ever had. She was dumb.

Even though she has many complaints about agency workers, Mrs. Erdman recognizes that they are poorly paid and do not receive health benefits if they work under 40 hours a week, so it is not surprising that agencies are short staffed. In the eight years that she received care, Mrs. Erdman had five good workers, "...when I say good, they were just as good as the bad ones were bad. They were excellent."

Personal Care Needs

Mrs. Erdman describes what she needs help with,

I need help with taking a bath. I don't get to shower that often anymore because the pain is unbelievable. I have more fractures, and the pain is unbelievable, but I do take a bedside bath. I can get a big basin and Ron fills it with real hot water and my lotions and soaps and stuff, and I can do my upper part, but I need somebody for my legs down, my feet, and my back, and also getting dressed, I need help. I can put my bras on, and my husband, he's got almost as many problems as I got, can't do a whole lot, and so I need help with homemaking and I need help with going to the grocery store, drug store, and pharmacy. Ron does the majority of all of that.

Regina describes the most important thing that her son Ron does for her,

I have to say homemaking because I hate to move. I hate to get up and get my bath, but he does that good, too. That's important, also, and skin care. My muscles ache and hurt all of the time and I've already got foot drop and

massaging with the lotion and stuff like that makes my legs feel better; a lot better. Certain areas below my knees mostly hurt all of the time and my feet, and you put lotion on it and plus it helps the circulation. So I would say both of what he does is important. Homemaking is important. Also every month he has to go pick up my prescription for my duragesic patches because that can't be called in or faxed over, and since I can't go there, they allow either my husband or son to go, and now for the last year Ron has been going because Gil don't feel like going anymore (he just had knee replacement surgery and is out of commission for six weeks). So everything Ron does for me, paid or otherwise, is important.

Regina also needs wheelchair transportation which she receives through the county. Her apartment complex has a ramp and both she and her son are very happy with the transportation service.

Caregiver Tasks

According to Regina and her husband, their son does many different things for his mother. Ron does laundry, runs errands, picks up prescriptions, vacuums, dusts, cleans the bathrooms and changes the bed linen. As Regina says, "He does an excellent job, too." Ron describes his caregiving as similar to the work he has always done for his mother,

I mean a lot of what I did before I got paid for, I still do now. The only thing that I do extra now is help with her skin care, you know, rub her legs sometimes and put lotion on her back and things like that. I help her write down sometimes some of the medications and keep track of that, but my dad does most of that, but I do a little bit also.

Basically, I am there to talk with her and offer a lot of emotional support because she does sometimes get down. She feels bad and has to be in the bed as much as she does and I will say, "Mom, it's okay. It's not your fault..." I try to give her that comfort and stuff. I mean I try to watch movies and TV with her.

As far as like work stuff, I help change her bed and things. She gets up out of the bed once a week. We help change the bed. Actually, my dad helps me with that, but I have done it by myself before also. I am not really the best cook in the world, so my dad basically does the cooking. He can't do much because he has bad health, too, but he does a few things. After work I will come in and just ask if she needs anything if I am on the clock or not. I will bring her sodas. I will make

her a sandwich or something. Sometimes she will let me know if she needs medicine. I will get it for her and then I will write it down, what time she took it. And then usually I will spend time watching some movies or watching some TV with her. These are mainly days when I am not on the clock.

Ron helped his mother before, but now that he is a paid caregiver he helps with skincare, changing the bed and laundry. Ron says that he gets a good workout when he works for his mother, "Cleaning all the tubs and sinks, I get my heart pumping a little bit."

Caregiver Schedule and Pay

Ron works seven hours a week for 10 dollars an hour. Mrs. Erdman says that she knows that 10 dollars an hour is a little high for wages, but she feels that if she pays well she will keep a good careworker and receive better care. Ron uses the money he makes for his care payment. Regina describes her son's schedule,

He works Monday two hours, Wednesday three hours and Friday two hours. The reason for three hours on Wednesday is laundry day. That makes seven hours. I get three hours on that one day. It gives him extra time to get the laundry done.

According to Regina, her son works more than the hours he is paid,

He definitely puts more time in than that. He helps us all of the time. There is not a day that goes by that he doesn't do something or more than one thing... He probably does about 20 hours a week with all the other things that he does beyond the seven that he gets paid for. He does a lot for us. He always told us that whenever he gets his own place or he gets married or whatever, he will always help us out as much as he can. He is a good son.

Ron thinks that he works "...at the most 30 minutes to an hour over maybe a couple of times a week here and there," but he feels that his hours and pay are good for now and that he can always "chip in" and do more for his mother.

My normal day of working is just Mondays, Wednesdays, and Fridays. I work seven hours a week ...When I am on the job (for my mother) I come right home when I get out of work. Actually, two out of the three days; I'm off Mondays and Wednesdays, but Fridays I will come home about 3:30 or 3:45 and then I will get

started. I will just do all of the housework that I have been describing to you. Then I will settle down and like I said watch TV with her and then if she needs extra stuff done, like me going to the store afterwards, I will just do it on my time off....

Ron also works in a 24 hour detox unit at a hospital. Because his hour at his job vary, Regina has to adjust his schedule at home occasionally.

Supervising a Family Caregiver

Regina was careful to make her expectations for Ron very clear. She explained that his first responsibility was to her and the work she expected him to do right away when he came home. If he was sick Regina called a back-up person she had in case of emergencies who was available until several months ago. Regina explains that she was hesitant to hire a family member at first,

I think that it is not a good idea to hire your family. It was actually my husband's idea of hiring Ron, and I thought about it, but I know my son. He's a great kid and everything, but I'm his mother and I knew beyond a doubt that he was going to want special favors. I knew it, and I knew that I was going to have to argue with him a little bit, and so we went around and around the first three or four times. Finally, he realized that he was working for me, but I knew that. Now I've got him just right.

This was his favorite thing, he would come in on Monday at 3:15 or he would forget (he was supposed to work from 3:00 until 6:00). I would say, "Ron, don't you have a job to do today?" "Oh, yeah. You told me 4:00." I said, "No, son, we agreed. Remember"? Finally, I made him write it out. I got it written out, so now he can't do that and he hasn't done it in a couple of months. He has really straightened out. He knows now. He comes in. I don't have to remind him of his time. I don't have to remind him on Monday, Wednesday, or Friday. He just does it. He says, "Mom, you are supposed to give a little bit." I said, "Ron, when you go to work, there are certain things that you are supposed to do and be there on time and clock in and clock out. Do they give?" He said no and so I said well there you go. I'm your mother. I said, "Am I overbearing on you?" He said, "No." I said "Okay. I will treat you the same way that I treat everybody else; no better and no worse."

I said, "When these two hours are over, you are my son again." It took him two times to get it, but he got it. For that reason, I can see where you might have family that swore to you (they would work for you and then not do the job). You

might have somebody that tries to steal from you. I think it depends on if you are willing to fire them or not, which I am. I told Ron real quick. I said, “You wanted this job and you asked for it, and I gave it to you. I will maybe give you two chances, but the third one you are gone. I want you to know that. I will not hesitate (to fire you).” He got it right away. That’s why I got him (as a caregiver) for a good four years; if I live that long.

Regina does not particularly like “being a boss,” but whether with her son or her previous workers, she keeps her eyes opened and makes sure that the people she hires do what they are supposed to do. Ron says that his mother treats him like an employee, “I do my best to be an employee, and I do my work hard and I do have a good job and everything.” Ron says that his mother’s expectations for him were clear from the beginning. His mother will tell him what she wants him to do and checks that his work is satisfactory,

She looks around afterwards and checks to make sure (that I have done my work), and my dad helps do that, too, because she can’t get up on her own and walk around to really check, but she does observe me from her bedridden position and she does have a pretty good view of the house when I’m doing what I need to be doing.

Advantages and Disadvantages of Hiring a Family Caregiver

Regina was hesitant at first about hiring her son, but she sees many advantages to receiving care from a family member,

It is good to have a family member because you feel more comfortable. ... A lot of people (agency careworkers) I have had in the past I trust, but it’s different. When you have family who come popping in every day or every other day, or living with you, I think anybody is more comfortable and happier. I believe that (is true) unless you got a crazy family that you don’t want to be around.

Regina thinks that hiring a family caregiver may cause problems if the family member decides to take advantage of the relationship and not work. Regina heard about a case where a daughter stole her mother’s money, “but I think that if a person is not senile or getting to old to see these things, they can take care of themselves.” Regina

says that hiring a non-family caregiver can be hard too because of the need to advertise and interview the worker.

The Caregiver Relationship

Regina speaks positively about her son Ron, “He is 28. He is a nice-looking young man. He is going to Junior College for two years and then university. He is a good worker.” When she asked Ron if he wanted to be her caregiver he told her that he could use the money and that he would like to help her because, “you are my mother and I love you.” Ron says that his mother hired him because she needed help and Ron needed the money to help him buy a car. Ron describes the relationship between him and his mother,

My relationship is great. I guess she gets offended sometimes by hiring a family member because there could be arguments or problems if someone does not want to work or get off early, but that is not the case at all with me and my mom. I do the job and she makes sure that I do the job. Sometimes I come home on Fridays and I’m tired from my job, but I still do the work. Sometimes I will take an extra 20 minutes to relax, but I will still do it. I don’t complain about it at all and I don’t mind helping her.

Ron adds that it was hard to get used to getting paid for the work he does for his mother, but that his new role did not change the relationship between he and his mother, “... it has just been a big help to me and I know it has been a big help to her.” Ron enjoys helping his mother because he cares for her,

She is a family member, and I love her very much, and she does have a need, and I do just enjoy helping her because I know that it makes her happy that I am able to make a little extra money and that makes her feel good. It makes me feel good, too, first and foremost because I am helping her. So, I would definitely say that I enjoy that the best (about being a caregiver) just because of whom I am helping.

Caregiver Worries

Ron does worry about his mother. It is hard for him to see how sick his mother feels especially on her bad days,

I worry about her all of the time because she does have a lot of severe health problems with her heart and her osteoporosis. I worry about her, but I know that when I'm not here, that she is in good hands with my dad and he has taken good care of her. He will come in and watch TV with her and do things with her when I'm not here, so I definitely do feel good about that.... She's always been the one that loved to do things and was independent when she had her health, and I would just love to be able to make her better.

Ron says that he and his father are always with his mother, they never leave her at home. Since Ron's father has developed health problems Ron is prepared to help him in the future, too.

Qualities of a Caregiver

Regina has a clear idea about the qualities of a good caregiver,

Neat and clean, to be on time, someone that doesn't run their mouth constantly. I don't mind if they talk a little bit, but does the job. I don't care if they work real slow. I don't care if they work fast as long as it is thorough and done right. I've had people that dusted half of the TV, but not the other half. That's how flaky they were. I swear to God... (I need) somebody that does the job, but does a thorough job. Not perfect. There's a difference.

Regina feels that her son Ron does a thorough job and does not cut corners even when he is busy.

Ron describes important caregiver qualities,

I definitely think that you have to be a hardworking type of personality, somebody who has a sense of humor and somebody that can communicate well and get along well with others. You need to be spontaneous and ready to go, ready to work when you are needed.

Ron would recommend the caregiver job to others,

The person that I would recommend the job to would be a lot like me... I think that they would definitely find a lot of success and a lot of personal satisfaction

with doing a job like this. I want to help people and not just family members; really anybody that I come in contact with.

Caregiver Experience and Training

Ron has been working for his mother for pay for four months at the time of the interview, but has helped her during the last seven or eight years,

... a lot of what I did before I got paid, I still do now. The only thing that I do extra now is help with her skin care, rub her legs sometimes and put lotion on her back and things like that. I help her write down some of the medications and keep track of that. My dad does most of that, but I do a little bit of that also.

He also works three days a week in the detox unit of a local hospital. Ron feels that his schooling as a psychology major helps him to communicate with his mother. Ron is too busy with his school, job, and caregiving to think of being a caregiver for someone else, but he thinks that working as a caregiver in the future would be a “distinct possibility.”

Use of the Cash Allowance

Regina uses her cash allowance for personal care, but she also has some cash left over every month after paying her son. She used to use this money to buy soap, but,

Now it's my medication. That takes it all and I have to add to it just to buy one medication with it. They paid for it for years, but in January, the company that my husband used to worked for changed insurance companies. I don't have an HMO or a PPO, and they don't pay for the medication now. So, the check that I get goes for the medication plus an extra \$15.00.

Regina's medication is expensive because she has to take the brand name medication and the insurance company, “won't pay unless it is generic.”

Working with the Consultant

Regina describes what her consultant does for her,

He has been out about three times total. He seems to know his business and what he is doing. He's a very nice person. He's helpful. He's willing to listen to

anything you have to tell him.... He seems to be somebody that's going to be pretty good. He always calls right back. When I call, he usually calls back the same day or if I call later in the afternoon because I don't like to call him. If he doesn't know about whatever it is, he knows who for me to call to find out.

Her consultant helps her with her Medicare waiver paperwork and paperwork for the Consumer Directed Care program,

We had already did it all ourselves, and he went over it and I think there was one mistake on our purchasing plan or something. He explained it and so we changed it, and then he came out the second time and checks all my receipts, and that was all okay. He was here twice or three times.

Benefits of the Program

Regina feels that there are many benefits to the program,

I think this (program) is not about independence of the patient, it is about cutting down the cost for the government and everything else. They can say independence all they want to, but it don't make me any more independent. It does not; at least it doesn't with me.... I have more control over my time. If I had (an agency worker) come, the agency would send some nitwit out here who sits down over there for 55 minutes and works for 10. You've got no control over that, really. So, I've got control of things like that (the worker), but that doesn't really make me feel any more independent.

Regina adds that, "I don't like anybody to have control of me as long as I got control over myself." The most important benefit of the program for Regina is that she gets personal care, but she is frustrated by the fact that the rest of her cash benefit is used to pay for one pill.

Regina mentions her ability to change the amount she pays a caregiver as an important benefit. If she lost her son as a caregiver and hired someone else she could decide to pay less per hour. She believes that the most important benefit of the program is the personal care and stated that it is "one hundred percent better to choose the personal care worker."

Ron describes the benefits of working as a caregiver in the program,

(The benefit is) the lower stress for the most part of not working in a regular job with a lot of people like a big company or something. Just working one on one with my own mother and you know only my dad being home. It's a lot less stressful atmosphere (than a company) and I would say that I really find that a big positive. The work that I do (is positive), It is sometimes hard work and running errands and things, especially with the way the heat has been. Sometimes that's not easy, but I'm glad that I have this car and it has a good air conditioner in it.

Neither Regina nor Ron found problems with the program.

Consumer Story 6

Richard Trappani is a 39 year-old single white male who lives at home with his mother and father in a two bedroom suburban house in the Tampa area. The house and yard are well kept and neat. Richard has muscular dystrophy, is quadriplegic, and breathes with the aid of a respirator. Richard's mother Margaret was his caregiver for many years and has cared for him throughout his life, but she is suffering from severe arthritis and is increasingly unable to help him. Richard also has a non-family caregiver, Lynn, who works 10 hours a week. Richard's father, who is 75, suffered a stroke and has recently been diagnosed with Alzheimer's disease. Richard has a brother and two sisters who visit, but do not live with him and his parents. Richard was dressed and well groomed and was in a hospital bed during the interview. He had some difficulty speaking because of the ventilator. He has a spacious bedroom furnished with a couch and chairs, a bureau with many photos, including photos of himself before he became paralyzed, as well as photos of his family.

Choosing and Managing Care

Richard received help through a local agency and heard about the CDC there. He liked what he heard about the consumer directed program and explained why he decided to enroll,

I am taking courses in business and business management, and I figured I would try it, and if I didn't like it, I could always go back to my original program. I would give it a shot, and I liked the idea of choosing and managing myself.

Margaret said that it was her son's decision to enroll although he talked to her about trying the program. Richard's consultant also mentions that even though he is very limited physically, he is very intelligent, and has been handling things very well.

In fact, Richard manages the money and care arrangements in the household for himself and his parents. He talks about his family's increasing needs with the consultant. He struggles to speak with the ventilator, but he tells the interviewer that he wants "to say everything that is important."

Things have changed. The consultant knows about it... I am asking for more (money). If I can't manage or I can't afford it, then I will definitely have to ask for (even more). (The consultant helped find) \$150.00 (a month for medication) and my father is getting three hours a day (for personal care). Someone will come in to give him a shower because when he came home from the hospital (after a stroke), they had tubes and my mom can't give him showers, so I had to find someone that would help him in the shower. My neighbor came and now he comes every day, two hours a day.

Yesterday my brother (was here). We got a letter and we opened it. For my dad, so we don't know yet if we can qualify for money. We have to meet with the social worker, so we can get his bills paid for. We will get about two hours (of personal care) a day at least. So, things are getting better. My father did not have a pension and all he gets is social security. It's approximately \$750 per month, and that's practically nothing... My mother only gets \$278, so that's what we live on, that's social security. The pills are like \$200.00 per month... I am sick and I don't go out. I mean I don't go to work. I haven't been sick, but I said that I'm a basket case if I have to go into the hospital.... You think you get the best care in the hospital, you don't. I would rather be home.

Supervision

Richard supervises his own care and takes care of the finances and his mother signs his papers. Margaret says that she signs his papers and takes care of his medications, but that her son is the "...boss, He says we are going to do this today and I say okay." Richard agrees, "I'm in charge. My Mom's at a loss, but I'm going to try

managing.” The situation at home has been especially difficult because both his parents are doing poorly. Richard explains,

I just love her so much... my Mom is in pain... If she is hurting, it's just as well that I'm hurting... it has been three or four months now (since she can help me). Even my attitude has not been great. She doesn't feel good... If my mom doesn't feel good, I don't feel good. I just want to mention that in the last three months, see my mom used to sleep here, and since my dad's stroke... my mom sleeps with him because he has fallen and so she doesn't get a good night's sleep like she used to, so that's why she is in bed a lot because she is up at night with him. So, mostly since 1993 when my father had the stroke, but my father would help me a lot because you need two people (to help me) to sit up... and when he had a stroke, things changed and we needed more help.

Richard is worried about the money and what will happen to his father if his mother is no longer able to help. He describes himself as a “worrywart.”

Previous Experience

Richard received agency help and also hired a local non-family caregiver out of his own pocket before the program. He continues to employ her through Consumer Directed Care, “She would come and she was like five minutes away, and she had two kids in school. She worked, and now she comes, so she has had experience.”

Margaret learned to care for her son through experience. She describes how she cared for him in the hospital,

Nobody trained me. I had to train myself in the hospital. I stayed a month... not learning (from hospital staff). It's just that he couldn't do anything and they wouldn't do anything for him. So, what was he supposed to do, just lay there? So I spoke to my doctor and I said would you give me a letter? I want to stay there. And the first day they fought it, but I got in there and they liked it because they never came into the room. I did everything for him. I fed him, and what I used to do was I got the big men to pick him up and to sit him up to eat and so they used to all call me mama, mama, mama, mama. So, I said okay mama you, you, you come with me. And they used to follow me up to his room while he was in the bed, too, and we used to sit him up. I used to get pillows, a piece of cheese, you

know. We used to sit him up and he would eat. And then they would say, “Tomorrow night, the same time?” and I said if you are around why not? That’s life. It was nice, and he was very happy because I was there with him. You know because he couldn’t have done it by himself.

Margaret says that at first she had trouble allowing strangers into her home,

You have to (get used to it) because I didn’t know that I had to have all these people. And then people used to tell me no there is this and there is that (program), they come help you. I said but I was bashful to have people come in my house. My house was always clean; it wasn’t because it was dirty or anything, but I don’t know. I just felt that way, but now I am out of it. I said I don’t care, whoever wants to come and is helping my son and helping the family... I won’t say no.

Needing Help with Everything

Richard describes what he needs help with, “Everything, pretty much. Eating, getting dressed, brushing my teeth, going to the bathroom, everything. Of course, medicines and cleaning.” Richard says that his condition is deteriorating and he is gradually able to do less and less. In the last three months his father’s condition has worsened and his mother’s ability to help him has decreased. For that reason, Richard’s consultant has renegotiated his monthly allowance to pay for five more hours a week of care.

Margaret says that she can no longer help Richard much because she has a fractured back after a fall and severe arthritis. She describes what he needs help with,

I will get his medicine ready, get his breakfast ready. Well, now health aides have been doing that because I have not been able to get up like before. They make the breakfast; they feed him after they dress him and we have a gentleman that washes him. He washes him. He’s an aide.

He’s got two days or three days out of the week... They give him a sponge bath fast. I can’t stand up and I can’t do it. They sponge him and then they put him in his chair, they dress him up and they go to the park or to the pool. He loves to go to the pool, at least to look at the water. The girls, if they want to go in, they go in. They feed him. I used to feed him when I was well. I got him a highchair,

but now I can't climb that chair with my legs. I always have somebody everyday (to come in and help). I have to.

Richard describes what his non-family careworker does for him,

She will come in. She will have breakfast in a little bit. She will make toast and give me my pills right away. She will come in my bedroom and come in by my side because I am on my back most of the night and she turns me and gives me medicine. Sometimes my mother makes breakfast. Lately my mom hasn't been feeling well, so she has to help more and then she will feed me breakfast and brush my teeth and then do whatever needs to be done. She shaves me. She washes my hair... Everything (she does) is pretty much important. I think, some of the most important things that Lynn does is that she is the only one that will wash my hair because it is not easy for one person to wash hair and there is a basin, and I have had other girls do it and it is not easy by yourself. Sometimes my mom helps. It's really a two-man job, and she can do it by herself. She handles almost anything by herself. She is in her 30s and she would go home and she would do her housework, and now she says she goes home and sleeps. So, I have aged her. She keeps me very clean and my skin is soft, and now she gives me soaps and lotions and shampoos and all of that. And the eating, (she helps with) two meals. The only thing that she doesn't do is I like to go outside. I say, "I like to go outside." I am cold and she is always hot. I like to sit in the sun and now she has a daughter who is 15 who likes (to take me), I'm always there. I go for an hour a day or two hours. It is shaded very well.

Margaret describes how she cares for Richard,

Suctioning him. He has a trach. It has to be suctioned, well these girls they don't know how to do it but there is this one. She was a nurse, I think and she is just a friend of my son passing by on the street. She said she would like to have a job. So, my son said can you pick me up, lift me and she said, "Yeah, I'm strong enough. And did you know how to suction because I don't make nobody suction, but the mother. Because you got to put something down his throat to suction the mucus. I do that. He has a G-tube, that's for his medication. I clean that for him. The tube, I change once a month. I take it out completely and sterilize it and everything. That's most of the things that I do for him.

Richard also receives help from unpaid friends,

I have friends. Mom is home 24/7. She doesn't drive and I'm in bed pretty much. My mom, if I need something, I get on the vent. I don't eat lunch. I have an Ensure shake at lunch because it is hard to swallow in a wheelchair, so I eat my breakfast; that's in the bed and so I have the shake or a piece of toast.

Schedule and Pay

Richard's non-family caregiver Lynn works 10 hours a week at \$10 an hour. Before the program, Richard paid her himself. According to Richard, Lynn is very dedicated, "If I'm in a bind over the weekend or she will stay a little longer. She goes beyond her hours. If I call her at any time and tell her that I needed her, she would come over..."

Margaret says, "There is no hours; it's just around the clock." Margaret gets paid for three hours a week at \$9 an hour for housekeeping. Richard had a non-family caregiver doing this before, but that person moved away. Richard likes being able to pay his mother for some of her time. Margaret does more work than she is paid for and comments about the pay,

It doesn't matter to me, but I don't even want nothing, but they said you work and you are entitled to it. (The money) is just a little something that I didn't even know I was entitled to it. And they said you want to get it, and I said all right but I don't do any less, I do more.

Like Family

Richard says that his caregiver Lynn, "She thinks she's family because I have been with her for years. She's like family, but she's not." Richard describes what is important to him in a caregiver, "Most of all (someone who) is caring, trustworthy, and someone I like, and who likes me, and most of all that works here and helps me..."

Richard spoke of how much he loves his mother and Margaret also spoke of her closeness to her son,

(We are) very tight; better than the other son. My other one, he's got a mind of his own. This one here (Richard), he is very lovable. He would be somebody's good husband and everything else (that) comes after that, but God said no.... You never get tired with him. You just keep going and going. He is a good guy. That's all I have got to say."

The Consultant

Richard describes his consultant as very nice, someone he can call with a problem.

Richard's consultant says that he does very well on the consumer directed program,

Richard has been doing a great job with it. I haven't had any problems with Richard. In fact, we are doing some work on him right now because he was getting a lot of informal service from living with his parents, and particularly his mother. His father is not able to do anything physically for him, but his mom provided a lot of informal help and now she got hurt and she is pretty much bedridden now. So we just did a reassessment on Richard, to up his budget. We are in the process; I'm probably going to be seeing him today, too, but he is doing very well with everything.

Problems and Benefits

Richard feels that there is too much paperwork on the CDC program especially when putting another person on his payroll. On the other hand, Richard says of the program,

It helps me a great deal. I get to choose the hours and the kind of help that I think that I could get is there, and it's fun... I like the one-on-one (contact)... I'm getting the same help, but I'm in more control. I get more help this way... I'm getting more hours with people I would rather have.

Consumer Story 7

Ms. Caroline Dunlap is a 63 year-old divorced white woman who lives with her sister and brother-in-law in a home in the Tampa suburbs. The house is well decorated as well as very clean and organized. Caroline had a stroke five years previously and has both diabetes and asthma. Her sister Beth is her representative and caregiver. Caroline was interviewed in her own room in her sister's home where she was lying in a hospital bed. Her bedroom has an air conditioner, a television, and a breathing machine and opens with a sliding glass door to a patio with many flowers and plants. Caroline's bed is situated so she can see outside and enjoy the view. Caroline was afraid that she could not answer the interviewer's questions and said that her sister Beth knew the answers better than she. Beth cried during her interview as she talked about her concerns about Caroline's health. We could not contact Caroline's consultant for an interview.

Previous Experience

Beth took care of her sister for three years before the program started. She has learned to care for her sister with some outside help and through experience,

I acquired (my knowledge of how to care for Caroline), I did get some pointers from physical therapy on how to (help her) and a nurse from the agency, (visiting nurses come out here. He showed me how to give her shots and how to do those sorts of things.

Medical Condition

Caroline describes her condition, "I had a stroke. My left side is paralyzed." Caroline is also diabetic. Beth cries as she talks about a medical problem Caroline had several months after she started caring for her,

Well, I brought her here September 30, 1997 and in November we ended up in the hospital with blood sugar of 540 and I almost had a nervous breakdown because I thought I was the cause of it. I just didn't know if I was doing the right thing. I

did everything I could and they said this can happen. Actually it was an infection, but I didn't know that I wasn't the cause of it. We have learned to cope with more now since that first episode because it was so new. As time goes on, it gets easier and we talk to people and people can help you out a little bit, tell you what they might do or what you might be able to do, or different things, so it does get easier. But that first time, I thought it was all my fault.

Beth also worries about Caroline's bleeding,

We did have a little problem because I was scared that somebody would come in and take her away because she was bleeding. It was just minutes – I left her – I had her rolled over just minutes before. I went in here to get something and I got back and she said, 'look what I have done,' she had blood running off of her hands – her skin is so tender. I get upset and scared... We had to rush her to the hospital at 3:30 in the morning for rectal bleeding from the Coumadin... I get scared because I'm worried that she won't quit bleeding. But other than that we don't have any problems.

Hospital stays are very hard on Caroline. Beth describes her reaction to being away from her family, "When I left her in the hospital she panics. They had to up her anti-depressant when I left her and she was crying constantly in the hospital."

She Helps Me with Everything

Caroline says that her sister and her brother-in-law take care of her. Of her sister Beth, "She helps to clean me because I can't get out of bed. She helps me with everything." In response to questions from the interviewer, Caroline agreed that her sister makes her meals, helps her eat, and does everything else she needs done because, "I can't get out of bed."

Beth does many things for her sister,

She is not able to get out of bed, so we have to do everything for her, from brushing her teeth to personal care and everything. Brush her hair, I cut her hair. I do her nails. I do everything she needs to have done. I usually clean her in the morning, wash her and clean her in the morning and again at night and then I get her ready for bed. She cannot go to the bathroom, so she is totally confined to the bed.

She gets yeast infections all over her body, from one end to the other, a raw mess and couldn't clear it up. She is very sensitive to antibiotics and she rejects antibiotics and I believe that's the cause of it coming out through the body, I'm not an expert, but they said it's from antibiotics and I feel like that's what it was. I used that spray can powder. Just powdered her down and that cleared it up, so I keep that on hand, and nothing else works. You have to do what you have to do. It doesn't always mean that's what we need next time it changes to this, it changes to that, it is a little hard to stay on that program as far as the money allowance for the supplies goes, because it does change. I didn't realize that at first.

(What we need to use) goes back and forth between powders, sprays, different creams. Neosporin is expensive, you know. With the diarrhea she is totally raw, bloody raw. I put Neosporin, a little tube \$7 and you go through two or three a week, for just that. But I feel like what's important to her, that's what I need to do, so I make this decision (to spend the money).

Beth is also careful to make sure that Caroline is never left alone in the house,

We are always here, but we go in her room with her unless we have something to do out here. Even my husband goes in and talks to her, you know. If I go to the grocery store, he brings her lunch and stuff like that. And sometimes he makes breakfast for her, and she enjoys that more than anything. He cooks her special soup because she likes it, things like that are important to everyone really.

Beth gives Caroline her medication and shots. She was scared to give the shots at first, but has become used to it. She must change and clean her sister 4 to 5 times a day,

It depends on how well she is or how sick she is. I cannot tell you honestly because there are days, she has really bad days, when you have to actually sit with her because she gets scared. And there have been nights where we sit together and there are nights I get up several times to check on her.

Schedule and Supervision

Caroline says that her sister is with her 24 hours a day, "She never goes to work; she is babysitting." Beth describes her daily schedule,

Well, I get up at 6 a.m., but not because of her, I get up at 6 and I try to let her sleep a little bit, but we wake her up, because it is time to wake up to give her coffee and clean her and start the day, and then we have breakfast. We have lunch about 1:00 or 2:00, then we have supper. I get her ready for bed around 8, by 9 she gets her last set of pills and then before I go to bed, I check on her again to make sure she is not wet or what have you, and then I go on to bed.

Beth does stay home all day and if she goes out her husband, her sister-in-law, or her granddaughter stay with Caroline. Beth estimates that she works with her sister for at least 4 hours a day.

Beth decides what do for her sister. If she needs medical advice she will call a nursing agency. If she needs help getting equipment (like a hospital bed) she calls the state consultant. Beth is careful to keep all her receipts and talks to her sister's consultant often. She does not get paid for all the work she does.

A Close Relationship

Beth feels close to her sister and feels that they have a good relationship. They often talk about "old times, new times, and her life in Michigan, we talk a lot." The quality of the sister's relationship often depends on how Caroline feels,

If she is well, we have a good time. If she is insecure about how she feels, it's not so good.... I sometimes get aggravated because she needs to talk about the same thing a lot because she forgets. We talk about different things. We try to brighten her life a little bit, with flowers and things and stuffed animals because it's hard for her to lay there all the time and you need to do something different.... I just like to have her here. I like to make her days happy.

Beth has her sister's bed situated so she can see flowers on the patio and the sky because when Caroline was in a nursing home for three months, all she saw was the wall. Beth feels that patience is the most important quality for a caregiver, "You have to love somebody to be able to do it. I don't think you could do it for the money, there isn't enough in it..."

Problems

The hardest part of Beth's job is transporting her sister to the doctor's office,

It's very hard in the summer because she doesn't do as well as she does when it's cooler, she can't stand up too well. ...It is hard to put her in a car and get her out in the wheelchair. Getting her in and out of cars is the hardest thing I have to do.

It is also very hard for Beth when Caroline goes to the hospital because her working hours do not change. Beth still has to clean and care for her sister.

Benefits of the Program

Beth says that the money Caroline pays her for caregiving has helped her sister, “It made her feel better because she don’t feel like a burden and it made me feel better because I do have extra money. It did make us feel better...” Beth feels that she can get help from the consultant to get things Caroline needs such as the hospital bed and the oxygen she uses at night. Beth’s granddaughter has also benefited because she has learned a lot bringing Caroline water and taking her blood sugar readings.

Consumer Story 8

Ms. Marta Covas is a 37-year old single woman of Puerto Rican descent. She lives with her mother and father in a suburban home in a middle class neighborhood in the Tampa/St. Petersburg area. Marta has cerebral palsy and is deaf/mute. She uses sign language (ASL) to communicate. She has the use of her arms and hands and uses a scooter to move around the house. Marta's mother, Alejandra, is both her representative and caregiver. Alejandra has cared for Marta since she was a child. Both Marta and her mother were well dressed and wore make up and jewelry. Marta also has a brother and two sisters who do not live at home, but come to help her and her mother. Marta's sister comes to visit and stay with Marta to provide respite care for Alejandra. Marta's sister also provides personal care, like cutting and dyeing her hair. Sometimes both sisters take her out to the park for the day. Marta's brother takes her to work everyday. Marta works in the McDonald's Training Center and Alejandra has a home business baking and decorating wedding cakes. Alejandra spoke in Spanish and answered most of the questions for herself and Marta. Marta did participate in sign language with her mother as interpreter. Marta smiled frequently and repeatedly asked for her mother's attention.

It's Bad When There is Little Work

The interviewer asked Marta about her job and she signed her answer to her mother who interprets,

They make pamphlets, folding, in boxes, putting screws, they have worked in many things, and sometimes they have a lot of work and some other times is boring. She likes it when there's a lot of work, she's like her mother, she really likes to work a lot (interpreting what Marta says)... a little bit of work is bad. She says it's bad when there's little work. She says she wants to save money to go on a cruise.

Marta continues to sign about her work after her mother stops translating and move on to other topics.

Family Café

Marta's mother found out about the Consumer Directed Care program when she attended Family Café, a yearly conference for people with disabilities that is sponsored by the Governor of Florida. Alejandra likes to attend because they have a good time and learn about new programs. She describes what attracted her to the program,

I decided to participate because this way I can be in charge of the budget for my daughter. I am very happy with it. Before she did not have a dentist, only what we got through Medicaid, and now I can look for my own dentist, and the people who can work for me.

Before enrolling in Consumer Directed Care, Alejandra said that they used Medicaid, but it did not provide much help and they were not able to get a psychologist for Marta. Marta also had a medical waiver and help from agency workers. According to Alejandra, "(We had one girl) who was just sitting here watching TV while Marta was all over the place. I want a person that comes and works with her." The family had one good careworker,

Once I had a lady who took good care of her, she would feed her, she slept here. She also had a daughter like mine. I even allowed her to bring her daughter here, so they were here... but it's not easy (getting help).

She Can Do Many Things

Alejandra describes all the things Marta needs help with,

She needs help with physical therapy, to learn to live by herself, like occupational therapy, independent living, something that helps her. One has to help her (getting dressed) because she's very slow, she can do many things, but I have to help her, otherwise she's late for work. She needs someone who knows sign language.

Alejandra also thinks that Marta needs to get out more and participate in different activities,

... I take her to the mall. She likes it, because being here (at home) she gets really depressed. We need more programs for people like her. (Programs) in the afternoons, so that she comes back and at least two or three times a week she can go somewhere to paint... , the social worker advises us to get her a computer, to give her what she needs, like to learn to use the computer... (Marta needs) someone who can take her out to a center where they paint, because she likes it so much, or any other place, for a hobby, because the time that I need to work is too much, it is very stressing. I want to have everything done (for her own cake business) by the time she gets back (from her job), and I cannot.

From the Moment She Wakes Up

Alejandra describes what she must do for her daughter Marta,

From the moment she wakes up, I have to put eye drops in her eyes, three different kinds, because she has glaucoma. I have to help her get up, because she gained weight. She's also on a diet because she's too heavy. I have to help her take a shower. I have to shower her while sitting on the toilet, because she's so heavy that I cannot hold her and I'm afraid to drop her. I help her dress, I also help her put on her makeup and do her hair, get her breakfast. I pick out the clothes she'll wear. I organize the money.

Now we are in the middle of remodeling the house, because her bathroom is very small, and so I have to help her. We also want to remodel the kitchen, because my kitchen is very small, and if we had a larger kitchen she could do all that (get her breakfast) by herself.

(My son comes to pick her up for work) and then he brings her back. When she comes back I sit with her and I massage her a little bit, because of the nerve (pain)... I put some cream on her. I get her on the exercise machine then I stay with her, play with her, and spend time with her. Do you see that ball? We throw it at each other. I take her to the mall. I also have to take care of the house, clean and all.

Schedule

Alejandra says that she works 12 hours a day. She is trying to find a non-family caregiver for 12-15 hours a week. The family hires a non-family caregiver to help on weekends,

She comes... well, this Saturday she cannot come. She works at the bank and she also does manicure, and she comes on Sundays, she takes Marta to church, and takes her out. She comes only Saturday and Sunday, and I am looking for someone else to help, but it's hard because since Marta is deaf-mute, not anyone can help. There's a girl who is learning (sign language), but it's hard.

The Cash Allowance

The caregiver is paid \$15 an hour, but Alejandra explains, "I don't get paid. The money that I get I use to pay (another caregiver), but nothing for me." Alejandra buys personal care supplies for Marta and the rest of the money she spends, "... on medical equipment Marta might need, a good bed, a good dentist, (since the program) there's more money for that."

When You Are No Longer Here This Child Will Follow You

Alejandra has cared for Marta since she was born. In addition to caring for her daughter, Alejandra runs a home business,

Baking, five days a week, because I also have to see my customers, decorate... and I've also been meaning to take a vacation, but I haven't been able to. It's been eleven years that we don't go on vacation. It's because I haven't found anyone who would take good care of her. Now with the program I can (hire someone to stay), but the girl is just learning to use sign language. I want her to help me so that I can go on vacation for at least a week. I hope I can do it!

Alejandra learned to care for her daughter "by doing and reading, watching, just based on the experience taking care of her." Alejandra describes the relationship between her and Marta,

We are very close, both of us. If she doesn't see me she looks for me everywhere, she doesn't give me a break for anything. Oh, yes (she looks at and signs to Marta)... you... mama resting.... you knocking on the door... she doesn't let me rest, knocking like this, she doesn't let me rest, and she goes looking for me everywhere. My husband says: "When you are no longer here, this child will follow you." Because I am the one who understands her, you know I take care of her, I spoil her....she fights with me when I am working. She doesn't want me to make any more cakes, or do anything else, but how would we live? That's why we need other people to come, so that I can do something else in the meantime.

Alejandra has difficulty leaving Marta for any length of time,

... Sometimes we have to deliver the wedding cakes, and the psychologist told me that when I have to go out, I have to explain to her that I have to leave her for an hour. Then tell her that if there's any emergency she can go out this way, and then go and stay out two, three hours, because Marta's already an adult, and she has to learn to be by herself, and that's how we are doing it now. Before we had to look for someone to take care of her, and I had to pay, and Marta knows how to get things from the fridge, she can get anything. That's why I want to get the bathroom fixed, and also the front of the house, so if she has to leave in an emergency she can do it.

Alejandra hopes that the new caregiver who is learning sign language will be able to give her a break, "I need to take a vacation, and she's going to tell me when she has her vacation, that way she can stay over."

Caregiver Qualities

Alejandra says that Marta prefers to be cared for by a member of her family, "This is the problem, she needs somebody that knows sign language. " I hope the girl who comes keeps helping. (Marta needs someone) who is nice, loving, she cannot stand someone who treats her bad."

Alejandra describes what is important to her in arranging care for her daughter,

... For me the first thing would be, a moral person, a person that would not only come and sit to watch TV and Marta was over there. No, I wanted a person who would come that has skills, learns sign language, and uses the computer.

Alejandra adds,

She prefers someone from her family (as a caregiver), I know that, but just like I've discussed with the consultant, in a few years I'll be exhausted, and she'll need someone else, or live independently. She's never been out (away from home), only for camping, and she would come back very happy, but in the future we have to think about that.

The Consultant Does Wonders

Alejandra is very happy with the program consultant. She speaks Spanish and,

She does wonders. As soon as I call her, she comes and really works to help us. One can even call her at night! I have never seen a support coordinator like her in my entire life. She's amazing. If she ever told me that she has to leave I'll suffer! ... They (the staff at the program office) have been nice to me. Every time I call they help me, the best thing is that they have somebody who speaks Spanish. They helped me, told me everything carefully.

Problems

Alejandra has not had many medical problems with Marta to deal with,

One time she had a very bad headache, one other time I fell with her, but other than that, no. At the beginning I was very frustrated, because I do not speak a lot of English, and I did not understand much, but then the social worker, who is very sweet, helped me and explained everything to me... The program is excellent, I am very happy. I've been here in Florida for 17 years. Now that I understand more of the program, because it was very difficult at the beginning, now that I understand more about the paperwork, it's better. For me, being Latin and not knowing a lot of English, it was hard, but I understand a lot more now. There is a consultant who speaks Spanish, I just call her and she helps me.

Alejandra says that the paperwork and material about the program is in English,

I understand much more now. I have a binder with all the receipts and all, the other day I went to bed at 1 a.m. filling out papers. Oh my God! There was a lot of paperwork that I did not understand, but thank God I already sent everything... and when I don't understand my son helps me.

As for improvements in the program,

I'd like to see if they could give more money, because I would like to find a place of "Independent Living" so that Marta can be more independent and also have people who know sign language, we need more people who know it, because my problem is twice as big, not everyone knows how to communicate. Sometimes it is really frustrating.

Alejandra mentions a language problem,

For me the most difficult thing has been learning the language, on the one hand to communicate with her because she's deaf mute, and also because of the English.

Benefits of Consumer Directed Care

Alejandra is very happy with the program,

It has helped to better administer the money, the budget, if she needs something. Before she needed a psychologist, and Medicare does not pay for one, but with this program we saw the doors open for us, and now I tell all my friends “This program is wonderful, you work, but you have a lot of benefits.” I am very happy.... If it wasn't for this program I don't know what would happen with me...

What I like the most is the fact that I see a lot more benefits with this program, and that makes me happy, because before I had to be calling the social worker, and now with this program I can look for the person I want myself.

Alejandra would recommend the program to someone else.

Consumer Story 9

Marilena Arroyo is a 27-year old single Hispanic woman who lives with her parents in a house in the suburbs of the Tampa/St. Petersburg area. Marilena is autistic. Her mother Sofia is her representative and her personal care worker. Marilena also has a friend who is paid to help her 20 hours a week. Marilena was simply dressed during the interview wearing jeans and a T shirt with her hair braided. She spoke to the interviewer with the help of her friend Anne. Marilena was very nervous, constantly twisting her hands during the interview. She had difficulty focusing, was anxious, but was able to participate in the interview. Anne spoke for her frequently and tried to keep her calm.

Marilena told the interviewer that she has autism. Sofia describes her daughter's behavior and says that what Marilena can do on any given day depends on her mood or what she wants. Sofia works with her daughter on social skills,

She doesn't have a lot of social skills, like when dealing with people. Today she called me when we were on our way here, to tell me that she had told a friend to come and right after she called me again and told me "I don't want her to come, I don't want her to come!" Well, I told her one has to tell her in a nice way, and she was yelling at me that she did not want her to come... She doesn't understand one has to be careful with people's feelings, so I have material and we work a lot with manners, how to deal with people socially. I've bought a lot of books on social skills and that kind of thing, so they do some sort of role-plays, with situations, to see if she can learn that way, and they help her get the right answer, to see if eventually in real situations she can use some of that.

Marilena is able to care for herself in some ways according to her mother,

She can make (cook) a lot of things, she can follow directions in the boxes, like microwave instructions, she can make some basic things, like rice, boil some noodles, and that sort of thing, simple things. But she doesn't want to do it all the time.

The consultant described why Marilena needed her mother as a representative,

Marilena as an individual has demonstrated and continues to demonstrate poor management skills. She would, at this point, not be able to handle the money

flow and that responsibility. She is very involved in expressing what it is she wants to learn or to do, which definitely is a good thing, and has lots of input and is indeed the source of structuring supports and services, probably 90% of the time.

Needs

Marilena describes what she needs help with, “I need help to get more people to be with me and I also need more people to work with me and help me.” Marilena says that she can cook for herself, but sometimes needs help to cook. She says that she can bathe herself and do laundry. Marilena says that on a typical day, her mother helps her wash her hair and her friend Anne helps her do worksheets in handwriting and math. Anne points out to Marilena that her mother does many things for her, “She cooks, she does your hair, she makes sure you have your clothes on matching, but you pick out your own clothes.” Marilena adds that her mother is with her “all the time.” Marilena says that the most important thing is, “she helps me wash my clothes.” Sofia describes what she does for her daughter,

She needs help with grooming, combing her hair, brushing her teeth, she cannot do it well, her personal cleaning, when she has her period. She needs at least someone to tell her how to do things, so in terms of grooming she needs a lot of help. She might dress herself, but one has to remind her to zip up her pants, or to fix her clothes, to be careful not to put it inside out, she doesn’t realize it, so one has to tell her. ... I cook her meals. Sometimes she does something by herself.

Sofia is careful that her daughter is always supervised,

I don’t leave her alone more than an hour. If I have to step out I make sure that she’s in her room that she has a movie, that she has something to eat, to drink, so that she doesn’t have any reason to come downstairs, because she still doesn’t understand issues of security. If anyone comes and knocks on the door (she would open it). I have left her a couple of times and when I get here I find her in the kitchen cooking or something.

If Sofia is out all day, she calls an agency and has a companion stay with

Marilena.

Schedule

Sofia works with Marilena for an hour and a half every morning getting her breakfast ready and helping her daughter get ready,

She gets up after eight, but she doesn't sleep in. Usually she's up by 8:15 or 8:30. She rarely gets up after that time, and it is then that we start the day. Sometimes if she's willing to then we work on math or reading something, an academic activity. It depends on her mood on that particular day. She goes through certain periods. There are times when she doesn't want to know about anything and she yells, and then there are other times when she's calmed down. Usually when she has her period she's unbearable for an entire week. She is violent, she doesn't want to know about anything. She wants to be locked up, she doesn't want to talk. She is in a bad mood. So, for this reason the doctor prescribed Prozac, but that didn't help her.

Supervision and Use of the Cash Allowance

Sofia interviews anyone who works with Marilena and she supervises their work. She uses the cash allowance in a variety of ways,

To pay the girls (who act as companions), also for speech therapy and massage therapy. Marilena had money for counseling services, but we changed it for Companion money, because she seems to get more benefit out of that. Also, we couldn't get a psychologist who had experience with autistic children.

Marilena's consultant does not have to do much work with the Arroyo family,

Mom is a brilliant manager and has done exactly what I think was intended for representatives under the CDC to do. My nightmare is when I have to interface with other agencies and the fiscal intermediary and that is my job to do that.

Caregiving Relationship

Sofia describes some difficulties in her relationship with her daughter,

Sometimes it seems to me that it's a typical mother-daughter relationship, she's in this period where we fight a lot, and I see a lot of teenage girls, and I see that she's like that, even when she's almost 28. She's in a stage saying "I hate you," "Leave me alone," "You don't let me do this..." and so on "You don't let me live alone, "You don't let me buy a car" and so on. (She has been like that) ever since her brother began to do things that she couldn't do. She was limited. When they were both children, her brother is two years younger, they could both do the same things. When he got a bike, she also learned to ride it, he learned to roller skate,

so did she. When he learned how to drive, she also wanted a car and wanted to learn how to drive. But she would have to study and take the exam... we let her study and try to take the exam, but when she took the exam she failed, and she tried again, but then she got tired and dropped the idea. But then, her brother got engaged, and she was happy while that was happening, because she was going to be a bridesmaid, but then when he got his apartment and married, now she's started again to say she wants to get married, get her apartment and leave. The problem is that she's very smart for many things, but she lacks common sense that she has to work. She knows a lot of things, but she doesn't seem to get why people do certain things. Then she gets angry. And then she says it's my fault, but I think it's normal for daughters to blame their mothers. I talk to her, look for books. Many times she understands better if she reads it.

Knowing about Autism

Marilena says that she wants anyone who helps her to be nice. Sofia thinks that any caregiver for her daughter needs to be very patient, but also needs to understand autism,

(If they don't know about autism) they don't realize that if they ask her something they have to ask in many different ways, in order to receive the right answer. Sometimes she doesn't understand if she's told something, but if you write it down then she might understand better. Sometimes they may ask her something and she's in a state of mind in which she might say "Yes" to everything and she's not really paying attention. You ask anything and she just says yes. Some other times she might have echolalia, for example if you ask her two things she might answer to the second thing you said, without paying attention. So many times, if I ask her something and the answer is important, then I write it down, and give her options a, b, c, you know I give her the answers for her to choose, but if I say it orally then she might answer with the last thing I said.

Sofia herself tries to learn as much as possible about autism, "I've read a lot about autism, every book written I get it. I've taken courses in the University of South Florida, I've been to many conferences." Sofia has worked as a caregiver for others, but says that her work for Marilena is different because of her emotional involvement with her daughter, "What she does affects me more than if it was another person doing the same thing. I would think that I leave and don't have to live with them." The best part of

caring for her daughter is “When she achieves something, when she does something I taught her.”

Problems with the Program

Sofia is happy with the program, but complains about accounting services,

I think the program is excellent. The only problem we’ve had was with the accounting, the checks do not arrive on time, and getting the correct statements, that they put the money in the proper category, and in sending checks, because for example, there were about five months when they did not send a thing. (Looking at a statement) For example, in here they say that there’s a deficit of \$5000, and I already explained to them, I sent them copies of everything, and they insisted, but they haven’t fixed that. So, they are the problem.

Sofia also says that participating in the program is not easy because she is responsible for so much, like interviewing potential caregivers.

Benefits of the Program

Marilena says that the best thing about the program is “getting the money.” With some prompting from Anne she says that she likes taking classes in speech, drawing, and dancing, and massage therapy. Sofia appreciates the flexibility of the program,

... for the speech therapy I can get the therapist that we want, we can get her more therapy, because we can negotiate the money, so she can get more hours of therapy with the same amount of money that we had before. With MedWaiver we had to use the therapists they indicated, and now I can get therapists from the community and the pay is less, so it comes out as more hours of therapy. The same happens with the massage therapy, we got a therapist who does it for less money and we can get more hours for the same money. We also have more flexibility in terms of the people who work with her. (The program is) worth it, because I think that you get better quality of service, and one is in control of the quality. One has a big community where one can get all the services.

Consumer Story 10

Mr. Kent Joyner is a 43 year-old divorced white male with Multiple Sclerosis. He lives alone in an apartment in a working class suburb and has a non-family careworker. Kent's apartment is well maintained and is in an apartment complex which was converted from a two-story motel with an in-ground swimming pool at its' center. He was friendly and seemed glad to have visitors. The apartment was clean and organized. The living room was decorated with many photos of family, including photos of his daughter who has not seen in six years, who he spoke of often. Also visible were Kent's wheelchair, scooter, and computer. The consumer was well-groomed and clean-shaven. The apartment smelled of smoke and Kent smoked throughout the interview.

Enrolling in the Program

Kent heard about Consumer Directed Care from his previous case manager who told him he would be a perfect candidate. Kent explains why he was attracted to enroll in the program,

... it is easier, I think, to hire friends and family and make some of your own decisions and not have to worry about can they get a hold of my case manager because that sometimes is hard.

Medical Condition

Kent was diagnosed with Multiple Sclerosis thirteen years ago. Kent explains what happened 8 years after his initial diagnosis,

I had two exacerbations and they took me down quite a bit. I was in the hospital. They put me on Medrol megadoses every six hours. I was in the hospital for two days and came home and then started getting all these nursing aides and whatever. You never know what the attacks will do to your system, but I get along pretty good.

Kent's left side is paralyzed. According to Kent, one of the problems with M.S. is that, "You never know from one day to the next what is going to work and what's not; what part of your body is going to (work or not...). Kent's non-family careworker Joan says that Kent has run himself into a dresser with his scooter and has also fallen, although never when she was caring for him. Kent wears a Medic Alert device around his neck in case he needs to summon help when he is alone.

Previous Experience with Agencies

Kent feels that Consumer Directed Care is much better than his previous experience with agencies. The worst part of using an agency for Kent was the turnover in workers,

I went through probably six different workers. I'm very tired by 10 a.m. and my energy level decreases as the day goes on, so when they got here later or called me to say that they can't come it didn't work. The agency would send somebody else or my caseworker would call another place (to find a careworker). I got tired. I had one girl that stole my cell phone. She would go down and do my laundry, but I didn't know if she was doing my laundry really or taking my quarters. I don't care if she (a careworker) is a few minutes late, but just get here. Don't call me and say (you can't come). If you are a few minutes late, it's no big deal, but when you get up in the morning and things are not working right, you know you need help and it's nice to know that the help is coming.

Even though Kent was unhappy with agency services, he liked his last agency worker who he hired through the program because,

Once you get comfortable with one person, they know how you are and you know how they are, and they know exactly what (you need), and I have a compulsive persona, and the thing that I like to know is that things are put in place, and Joan knows that and she will put things back.

Joan is a licensed home health aide who worked with Kent through an agency for a year before he started on the program. She decided to continue to work for Kent on the

program even though she took a pay cut because, as she explains, “I felt that it would have been detrimental for his emotional well-being to just drop him.”

Needing Help

Kent describes what he needs help with and what he is able to do himself, “Personal care, food, meals. Those are the three major things (I need).” Kent needs help with homecare as well, although he says that he tries to keep things clean in his apartment. His second non-family caregiver helps him with house cleaning.

Kent has a meal service which helps him take care of some of his own needs,

When the food gets delivered, it is all ready. I can make my own coffee in the morning. My dishes, what little I have, I can do myself. If I am staying up here (in the apartment), I use my wheelchair in the kitchen. I get along pretty good. I can go to the refrigerator.

Kent adds that he can’t make his own bed, but that he can sit at the computer in his wheelchair. He uses his scooter when he goes out and can do his own grocery shopping and banking. He has a car, but he explains that he is “grounded” when it rains.

Kent relies on the personal care he receives from Joan,

She bathes me in the shower. She helps me in the shower and she makes my bed...she helps get me dressed, anything I need. She will normally make coffee in the morning. If my garbage needs taking out and my homemaker is scheduled for Monday and Friday she will take the garbage out. She will just make sure that everything is tidy. She is a real big help.

Kent thinks that bathing and dressing are the most important things that Joan does for him.

Joan describes her work for Kent as, “Homemaking, personal care, and errands.”

Joan straightens his apartment, prepares meals and assists Kent with showers because of his left side paralysis. Joan describes some of the work she does,

I empty the coffee filter and set up the coffee, roll up the cord on his scooter, fill up water jugs, water plants, and (cleaning) he really can't do any cleaning. If he drops something on the floor he has to leave it, but it is difficult for him to retrieve it back. When I first started seeing Kent, I did arrange for him to have a shower seat because before that, he was standing up and holding on with one hand. That was tough.

Caregiving Schedule

Joan works four days a week on Monday, Wednesday, Friday, and Saturday for an hour and a half each day. Kent gets up at 5:30 in the morning and is already up when Joan arrives to help him. Joan says that she works, "... first thing in the morning from 7 o'clock until 8:30 four days a week."

Caregiver Pay

Joan worked for Kent through an agency before he started on the Consumer Directed Care Program. Kent liked her and wanted to keep her,

... her agency lets me use her (Kent hires her through the agency). She knows me and I know her, and I am very comfortable with her and so when I couldn't hire her directly, I had to hire the agency, which is \$17 an hour. She doesn't get that much. But, that's why I had to do it in order to retain her services. I think (she gets) only like \$9.50 or \$10 (an hour)[the agency gets the rest].

Kent has a monthly budget of \$1,036 through the program.

Joan took a \$1 an hour cut in pay to keep working for Kent. Before the program she made \$10.50 an hour, now she makes \$9.50 an hour even though Kent pays the agency \$17 an hour. Kent had a second non-family careworker who helped him clean, but she quit because he could not pay her more money.

Supervision

Kent says that he supervises Joan's work. Joan says that, "I just let him prioritize what needs to be done for that day, but it is always personal care (that comes first)."

Caregiver Experience and Future Plans

Joan is a licensed home health aide and she feels that it is important to have training, “You definitely need training, especially with someone who is disabled or physically challenged.” Joan plans to continue this type of work, “I would like to go back to school and further my education, either as a medical assistant or in nursing.” Joan does not feel that her experience working with Consumer Directed Care differs from her work with the agency, “It is basically the same. It doesn’t matter who writes the paycheck. The work is still the same, and it depends on the person, too. Some people think of it as a job. I think of it as a career.”

Caregiver Qualities

It is clear that a stable caregiving arrangement is important to Kent. He also thinks that a caregiver must be honest, have integrity, and be trustworthy. Kent thinks that it is better to have a non-family caregiver than a family caregiver. Kent has a friend who is helping him and although he is not specific about why this arrangement is a problem, he comments, “A friend of mine is helping, but he crossed the line... you can’t cross the line between friendship and this. It’s a very delicate, fine line and you can’t cross it.” Kent also says that he would not want his mother to help him.

The Caregiver Relationship and Stresses of the Job

Joan describes her relationship with Kent as professional. Joan likes working for him, but it bothers her when he becomes upset,

He has a good attitude on most days. It is frustrating, for example, if he is trying to write a check in his checkbook and tear it out, it is almost impossible with one hand. I asked him, “Look. Can you please let me do these things while I’m here and then when I’m not here, you can pound on the table.” To see him when he is trying to complete something and there is a lot of frustration and it does make him upset, and so that bothers me a little bit because I don’t like to see him get upset.

Other Use of the Cash Allowance

Kent used his cash allowance to have a wheelchair ramp built outside and to pay for termite extermination.

Problems with the Consumer Directed Care Program

Kent found the program very confusing during the first six months, but that it is “coming around” now. The consultant is helpful, “For the first four or five months, (the consultant) was kind of new at it, too, so I had a couple of questions that even (the consultant) couldn’t answer, but we got it worked out.” Kent also has problems understanding the financial statement and feels that he must be vigilant about seeing that all the bills are paid. He worries about what he will do if someone wants to be paid in cash, but he can only get checks through the program. Kent feels that things are going more smoothly now that he knows how the program works. Kent’s consultant felt that it was difficult for Kent “to do his own case management,” because the actual work of managing your own care is not very glamorous. The consultant thinks that consumers like the idea, but are not always prepared for all the work involved on their part. Kent says, “Once you know your responsibilities, it works out great.”

Benefits of the Program

Kent describes the benefits of the program,

You are able to make some of your own decisions about what kind of help that you can get instead of having to rely on a case manager through an agency who sets you up for the help. You are allowed to make (decisions) and by hiring family, it is your responsibility. It’s not theirs and you are allowed to (decide who does what), my neighbor next door, for instance, is cooking for me. But it helps as far as basically being able to make your own decisions about the kind of people that you can hire to help you. That’s what I like about it. It gives me something to do.... I make choices myself. The most important is the choice not having to contact agencies.

Kent would recommend the program to someone else because “You are the case manager, you are in control.... I don’t want to be dependent. Somebody else doesn’t know what you need. You do.”

Consumer Story 11

Paul Farmer is a 10 year-old African-American boy with Down's syndrome who lives in a low-income suburb of Tampa with his grandparents. His grandmother Emma acts as his representative and caregiver. His grandfather William and a non-family caregiver each work 80 hours a month. The Farmer's house was simple and clean. Paul sat in the small living room wearing only a diaper while playing with toys in front of the television. Paul communicates using American Sign Language, gestures, and also uses a Dynovox, which is a computer that has icons illustrating actions and objects to facilitate communication. Emma Farmer answered the interview questions for her grandson and the other caregivers.

Enrollment

Emma heard about Consumer Directed Care from her consultant who was already working with their family in another program. As Emma says, "My consultant thought it would be a good idea for us to join the CDC because it would be a better way of getting supplies and some of the services that Paul needed."

Feeling Confined

According to Emma, the Farmer's previous experiences with agency services were not always positive,

(With agency services) we were like confined or had to find another family member that could come in and watch Paul if we wanted to go somewhere. Or if we wanted respite care we would have to ask for it a couple of days in advance to see if someone (from the agency) was going to be available to come in. And then the agency would have different people coming in and out of your house – I didn't particularly like that. It was not just one person, it would be different people. Paul would get used to one person and then they change and you'd have somebody else.

Helping with Daily Routines

Emma describes the help that Paul needs,

He needs help with his daily routines; he is not toilet trained so he uses diapers. That's been a big help, buying the diapers. Before I was buying them out of pocket and that's very expensive. He needs help with just about everything that a normal person would do on their own. He's not toilet trained so we have constantly to change diapers and stuff. He needs help with bathing, brushing his teeth, combing his hair, putting on his clothes.

Around the Clock

Emma and her husband work hard at caring for their grandson,

Well, with me and my husband it's a round the clock thing, from the time you get up to the time you go to bed. But as far as (paid) hours are concerned, my husband basically puts in about 80 hours a month.

I work outside of the house and I would have to take off from work in case Paul needed to go to the doctor, that's where my husband comes in. He takes him to the doctor, takes him to the doctor's appointment, where I don't have to take off from work. Also, if the school needs us for any reason, like if he gets hurt on the playground or something like that, they can always call my husband and he can go to the school and see what's going on. The same with the non-family careworker, she's available, the school has her number to give her a call in case they can't reach my husband or myself. Or if I'm not able to get there in a certain length of time, they can always call her. She can go and see what's going on.

Emma describes the non-family caregiver's schedule,

Her weekly schedule is during the school term, she'll pick him up from school and keep him until 5 o'clock in the afternoon when I get off from work, and either myself or my husband will pick him up. And on the weekends if we want to go to dinner or go to a movie or something like that, I can always call on her and she'll keep him for a couple of hours for us. (Her hours) vary, because during the school term she doesn't have that many hours and during the summer she will get more hours because Paul's not in school, so it varies according to what time of the year it is. And holidays, if we decide to go somewhere, she'll keep him.

Pay

Emma receives no pay, but both her husband and the non-family caregiver receive \$16 an hour and each work 80 hours a month.

The Cash Allowance

In addition to buying diapers, Emma uses the cash allowance for her grandson's needs,

His clothing, like because every other week he's in a different size, so I'm continually buying clothes for him in order for them to fit, that type of thing. The bicycle was purchased from the budget. It's an adaptive bicycle for disabled people and it has the foot restraint, and the back support. Where he wouldn't be able to ride a normal bicycle, this helps him hold his balance, and it's also stationary, where if you just want to exercise on it you can do that and you can take the exercise part off and make it a regular tricycle and go out and ride it.

Qualities of a Good Caregiver

Emma's idea of a good caregiver is, "someone that's compassionate, someone who has patience and can deal with a child with special needs." Emma hired a non-family caregiver who worked with her grandson Paul with a previous program,

I just continued to use her after we got on the program because she was very good with him, and knows his routine, and she picks him up from school and just takes him wherever and if he needs to be taken she keeps him, like if we need to go out of town she'll keep him overnight, that type of thing... Non-family (caregivers) are good because it gives the child an outing, not confined to being home all the time, and Paul basically can be around other people.

A Helpful Consultant

Emma is pleased with the consultant,

She's very helpful. We don't have a lot of contact because I have very few problems with the program, but anytime I have a problem I can call her and she calls me right back and it gets resolved. In the past, she's helped me with keeping my budget straight. If I had any problems with "PAS" (Personal Assistance Services) she would call them if I needed her to, that type of thing.

Paul's consultant says that Emma does not need much help,

She's extremely competent. She's extremely independent. I'm not going to step in where she feels that she's getting what she needs...I've provided her information on where to get resources. I have provided her information on how she should deal with employees. I have provided her information on basically what kinds of equipment and what kinds of services she can expend money on and what she can't, and like I said, she often has already expended it once I find out.

Problems

Emma's problems with the program are minor,

I haven't had any problems with the program except for the statements that PAS hands out. They are very difficult to read for a normal person and that's the only problem I've had with them.

According to the consultant,

My clients have been pretty screwed up at the accounting level. It's very frustrating and the problems are ongoing, but the problems were much worse in the beginning than they are now. I don't know if things are getting easier or consumers have just given up. I'm not sure. They put them through a lot to begin with and they (the consumers) are kind of used to beating against the wall instead of walking through a door and they get tired of it.

How I resolve problems with PAS. Five or six phone calls and hope you get a call back. They continue to take money out for taxes where clients should not be paying taxes... They continue to do things like that. They also give misinformation to the clients. They tell them that they need approval for something that they don't need approval for, and they don't read the plans, and they deny things that they should not be denying. My guess is that they are overloaded.

I hate to be negative. Sometimes I feel with this system I am put in a position where I am approving something because it has already been done. That would not be approved on the regular Med Waiver Program. It could get me into a lot of trouble. It's an uncomfortable part of the program... There have been some problems on this case with purchasing and feeling like I am put in a situation where I am being asked not to be honest, and I can't do that. In reality how much do I know about what the consumers are doing with the money? I'm not auditing their bills every month. They are not coming up with the bills every month. If I was doing something like that, they may as well be on the regular program.

The Freedom It Gives Us

Emma describes what she likes about the CDC program,

It helps us by giving us some freedom because we have an outside caregiver. A personal care assistant that helps with Paul, and it gives us some freedom in case we want to go out, we can always call the outside personal care person to take care of him outside of the home. Because before, the services through the Children's Medical Service that we were receiving, if their funds were cut, then our services were cut as far as consumer products and respite care so this program helped out. We know we have a set budget and we are able to continue on a month to month basis as far as getting consumer products and not having to come out of pocket. The benefit is the ability for the caregivers to control the budget – at least you know where the money is going and it gives them the freedom to be able to say how the money is being spent. Where before, it was in one agency's hand and you didn't know if you were getting what you were entitled to.

Emma says that she would recommend the program to others,

I would give them the advice; get on the program if you can. It's very helpful and very beneficial. It gives the caregivers some freedom and the ability to be more relaxed and not so confined all the time.

Consumer Story 12

Sarah Sullivan is an 8 year-old white girl who lives with her mother and father in a middle class suburb of Tampa. Sarah has cerebral palsy, is quadriplegic and uses a wheelchair, and also has developmental disabilities. Sarah's mother, Jennifer, is her representative and her grandmother is her personal careworker.

The interview was conducted in the Sarah's home with her parents Jennifer and Mike who answered all the questions. The home was clean and bright and had been remodeled for improved access for the consumer's wheelchair. Sarah was nicely dressed and seemed interested in the interview process, wheeling in and out of the living room periodically. Sarah's grandmother cares for her before and after school and in the summer while her parents are working full-time jobs.

Sarah's Disability

Sarah's mother, Jennifer describes Sarah's medical condition and needs,

She has cerebral palsy and spastic quadriplegia. She doesn't sit, walk, or stand independently. She is mentally impaired as well, although it hasn't been officially determined at what level yet. I don't have the doors right open there, but she has some severe orthopedic impairments... She can pretty much say [some things]. Not as well as other children, but she can say, "Mommy, are you hot?", meaning "I'm hot, Mom," Things like that.

Sarah's father continues with a description of her speech,

She has a developmental delay with her speech. You can understand her but, she may say it a different way. You have to determine or discern from when she asks if Mommy's hot, that she's hot, but . . . and there are other times where she can just [speak clearly] and she'll say something like, "Mommy, I'm thirsty" or, she'll speak of herself in the 3rd person, she'll say "Sarah wants some Boost." That's what she'll do.

An Efficient Program

Jennifer described why she and her husband decided to enroll in the Consumer Directed Care Program (CDC),

It seemed like it would be a lot more efficient. I wanted more control and I think a lot of parents, at least my friends feel like we're the last person to be consulted about anything. You can't get anything without a doctor's prescription even though you know your kid better. I mean I'm not talking medication, I'm talking about simple things like orthopedic braces. We end up calling the doctor because most of us are on very good terms with our physicians and saying, "Hey, I need a prescription for (whatever). Can you get it for me?" and they do it. So it's like we are thought of (as) so lowly by so many people who supply the services and insurance companies and everybody else, CDC was a way to at least get some control, because, we are ultimately the ones who are making decisions for our children. I feel like we're the captains of this team and yet nobody seems to understand that. There's nobody, there's no one professional person out there saying "Here's what you need to do for Sarah. You need to take her to an orthopedist. You need to take her to Shriners, too for this. You also need to take her to a neurologist and see what they say, but make sure they talk to each other. Because they (the doctors) don't (talk to each other). You need to get this standard for her because that's the best. Nobody says that. They say consult your physical therapist who says, "Look, talk to your occupational therapist." So you have to be the hub of that wheel and nobody who is supplying the funds seems to understand that and that's very, very frustrating, so this project really, really appealed to me because, like, finally, maybe we can actually say, "Here's what we need, here's what we can do to get it, I can find it cheaper over here." You know? Let's get over some of these hurdles. That's why CDC was appealing to us.

Around the Clock Care

Jennifer describe what she and her husband do for Sarah,

Pretty much everything. She can feed herself with assistance. She can actually use a spoon, but we have to help. We do all of her pottyng. She is still in diapers, but we do put her on a potty chair. She has a schedule that she goes on, but she's still relying on diapers. We bathe her, get her up in the morning out of bed, lift her in her chair, help with her homework, cart her around to doctor's appointments, take her to therapy, we do her exercises every day. She is totally dependent on us.

Captain of the Team

Jennifer and Mike have developed an expertise in caring for their daughter.

Jennifer describes how they learned to care for their daughter,

Mostly trial and error. I mean, we've been taking care of her since she was an infant. Initially, when we brought her home from the hospital, she was very, very sick and we had some instructions from the physicians that she had more medical conditions than she has now, you know. But it's just kind of trial and error.

Mike stresses the importance of learning by experience, "You just get a diagnosis or prognosis and you know basically what you're starting with but, as you go you learn things, just like raising any child, I guess. But with special needs, it's more involved."

Mike says that he and his wife receive advice and input from many different people.

According to Jennifer, everyone has ideas about how to best care for Sarah,

... and our therapist, and her orthopedic surgeon you know has ideas, like you need to make sure that she stretches out her hamstrings everyday and you can do this in this way, this way and this way, so you know we follow their advice and do it that way. They say to do floor sitting, but like you can see, her now, we've got her propped up in front of the TV with her legs on a Huggie box doing it that way, because she's more entertained and it doesn't take our time, so we've kind of adapted.

And with children and I know that most parents feel this way, you feel that you are the captain of the team. Most of us have very good relationships with our physician and you know, I have no doubt that I could call my pediatrician right now, get a hold of her and get a prescription for Sarah over the phone based on what I'm telling her, because she knows me. I know her. She knows how we are ... she wouldn't give me a prescription for anything too off-the-wall but if it was something that she knows is consistent with her diagnosis, she would. And the orthopedists are the same way. They give us suggestions, we decide okay, well, here's what we're going to do... The orthopedist doesn't really care how a child does in school. For instance, one of Sarah's orthopedists says Sarah should sit straight-legged at school all day long, or most of the day. Well, that doesn't really work well, because she's got other things to do during the day and so we have to modify what they're telling us. Another one wants her to wear a brace which we have and she wears sometimes, but we had to say, "Well, we respect your opinion, however, what you're forgetting is that the kid wears diapers." or what good is it if she's standing in the brace and we can't get the diaper off? You can't put a diaper over it. So, although that's a really good orthopedic thing, the brace

is not really practical for my daughter in that sense. So we, as parents have to say, “great idea for her orthopedic needs, however, globally, it’s not such a great idea.” Maybe Sarah can’t wear it to school, because she’s got aids who diaper her and if you take the brace off, she crumbles. I think we (the parents) are the supervisors of everybody else. . . . That’s how we view it. Nobody supervises us. We supervise them and put it all together and say, okay, a little bit of you and a little bit of you and a little bit of you.

Scheduling around Sarah’s Needs

Both Sarah’s mother and father work full time and they must schedule their jobs around their daughter’s needs and schedule. Jennifer describes the important schedule issues,

Both of us have outside jobs and, fortunately, I am able to work out with my employer that I can work in the afternoons at home from my office here, so my husband has to be at work at 1 and I get off at 1:30 and the school bus gets here at 2:15, so I’m shooting home to get the school bus. During the summer time, we have Camp Sparks, which is an all day thing so I try to get her around 2 because that’s too long for her, to be away all day. Anyway, between our schedules, and he has quite a bit of vacation time, which he has scheduled all around Sarah’s school schedule and days that we don’t have care, and between that and then my mother, she’s a snow bird, so she’s down here during the winter months, she help us out when she can, so we manage to do it ourselves... We have a couple hours that we have trouble with...

Sarah’s father Mike describes the start of a typical day,

Well, a typical day starts with me. Jennifer goes to work about 7 (a.m.), I believe, and so I wake Sarah, depending on whether or not she has school. I’ll wake her, dress her and give her breakfast, which consists of her Boost, mainly, and prepare her for whatever--school or camp. I pack her lunch and whatever she needs; the supplies she needs and most of the people at school or at Camp Sparks are aware of her situation. That’s all I do, basically.

Jennifer continues,

That’s in the morning. Then I race home to get her off the school bus and until recently, two days a week, took her to therapy, every two days and we always have a doctor’s appointment at least once a week it seems. In fact, we have one Monday. Mike’s going to take her to and drop Sarah off at my office, like a constant tag team thing. But then in the evenings, we do homework when school is in. We do whatever exercises we have to do. We take a bath then I put her to bed and that’s her day. Then on the weekends, because I can’t stand doing baths--

I hate doing baths and she's getting heavy, Mike does the evening rituals to give me a break.

Mike and Jennifer's tight schedule is eased slightly by hiring Jennifer's mother as a caregiver. Jennifer describes her family caregiver, who she refers to as the respite worker,

I have a family person that I pay that worked out very well. As a respite worker, we've used my mother when she's down here (in Florida). That's worked out really well because Sarah won't stay with anybody else and it's very hard to find anybody that's qualified that's around for any length of time consistently, so finding someone in my family . . . she's just been available to us because my father just retired. She doesn't work. She's basically somewhat disabled because she has trouble with her hands, though she's had lots of surgery for carpal tunnel and tennis elbow—anyway, she can't work otherwise, so this is a nice little income for her. She gets like \$300 a month for respite care. Of course, I think we told her we'd pay her \$10/hour, which is only 30 hours a month. She has Sarah a *lot* more than that and she doesn't get paid for it because she's her grandmother and she loves her. But it helps her out immensely. And it's made her feel good, like she's helping us.

Mike adds,

And it's wonderful for us because their (my in-laws) schedule is so flexible. Like there's times when Jennifer has things she needs to do and I have my work schedule, and someone needs to be here and you can just call them and they can be here. And an outside person we can rely on like that . . . (is very convenient).

According to Jennifer, her father is a big help, too,

I shouldn't leave my father out of this. We're paying my mother and it's her job, but my father's there all the time and he's doing the lifting . . . I mean my mom takes care of Sarah, but he lifts her on and off the potty, gets her out of her chair, you know. We had an ancient potty chair that we gave to them and then we got her a new one that's a little better and easier (to use) for our home so my parents have a potty chair down there too...

For both Jennifer and Mike, the availability of Sarah's grandmother for respite care is an important advantage of the CDC program. Jennifer says that she is sometimes caught in traffic coming home from her job to get Sarah. Mike describes what happens,

And you're panicked, I mean you're panicked. If Jennifer calls me and says "Hey, can you go into work late because I'm stuck in traffic," and I'm already on my way (to work), by the time I get back, Sarah's bus would probably already be there. So, we call Jennifer's mom (finger snap) mom can come right out.

Jennifer says that they cannot get that kind of help from anyone else,

Even our friends, we have a few friends; Sarah's friends, actually, their parents; we're all kind of in the same boat so we would do that for each other, but the chances finding them available to do that when we're in a crisis is one to none, because, you know, they work too.

Mike and Jennifer can only call on Sarah's grandmother half the year when she comes down to Florida. Mike says, "The rest of the time, both of us have sacrificed time at work because Sarah comes first no matter what." Jennifer says that it is lucky that her husband gets vacation days he can use.

During the summer, Jennifer describes how they rely on summer camp for their daughter,

The only thing that (helps us in the summer) is the county summer recreation program for disabled children. I don't know what we'd do in the summer time (without it), because my mother is not here, there's no daycare or anything like that so we would have a problem.

The summer camp program for disabled children up to 21, it only costs \$75 for the entire summer, and they actually have programs for typical children as well. They're hard to get into. I mean there is a waiting list and all, but I don't know what we would have done without that ...

Her Grandmother Loves Her

Jennifer thinks that the relationship between Sarah and her grandmother is an important one,

My mother thinks that grandmothers should be obligated to do that sort of thing. You know, we tell her, it's work (to care for Sarah). And she knows it's work. It's just that she loves her granddaughter so much. Unfortunately, some women cannot (work for free so much), because their choice is, "I either work and make money, or I take care of my grandchild and don't make money. I have to live. I

have to eat.” And this (getting paid for caregiving) has helped my mother tremendously. With my dad retired, things are tighter.

Patience is also an important attribute for a caregiver. Mike describes their early attempts to understand Sarah,

(A caregiver) needs to be someone with a great deal of patience for this. Early on with Sarah’s communication, it was not very good. We’d have to listen to things, you know, over and over and she’d get frustrated cause she’d have to say them and then we’d bounce them off each other and then finally, (snap finger) Oh! Yes . . . now, now it’s a lot easier to understand her, so. . . it’s got to be somebody with a great deal of patience.

Consistency of Caregiving

Jennifer describes important qualities in a paid caregiver, “Consistency. Dependability. Sarah doesn’t do well, if she has a new one a week. She has to get used to that person. So we need someone we can rely on.”

Jennifer feels that her mother’s consistent care of Sarah is very important,

It helps Sarah immensely. Yes, it helps my mother. It helps Sarah because she does have the chance to spend more time with her grandmother. It helps us because if I feel like I’m paying somebody for something, even if it’s my mother, I don’t have a problem asking her to do it. Otherwise, you know, she’s retired, I don’t want to ask her to take her time to pick up my kid or, can you meet the school bus, you know. I don’t feel as guilty if I know that she’s going to get that check, insignificant as it is. . . . your parents might have been doing you favors for years. It’s harder to just ask them over and over and over.

Use of the Cash Allowance

Jennifer and Mike have found many uses for the cash allowance. They used some of the money to build a ramp for at her grandmother’s mobile home so that Sarah could stay there occasionally,

I use my savings to buy a ramp because Medicaid never would have bought a ramp for *their* home. So, it’s nice for Sarah to go to her grandmother’s house, and that’s the only way to get her in. We’ve just got a 300-pound wheelchair. We can’t carry it, so the only way she can go to Grandma’s is if Grandma has a ramp. Now Grandma wants to do some home modification, like making the door wider.

She's going to use the respite money to make the door wider because we know the Medicaid Waiver wouldn't pay for that. So it enables my daughter to go to her Grandma's house, which I think is very important.

She (Sarah's grandmother) actually has a hard time getting paid for this, "I'm the grandma. I shouldn't get paid for this." So the first check she got, she took her check and got Christmas presents. And that was a good thing for her; a little more (presents) for Sarah. She has a hard time spending it on herself. She wants to take us all out to eat when she gets her respite check. It's good for her and it's good for Sarah. She (Sarah's grandmother) has a hard time with it (taking money).

Jennifer describes the advantages of the cash allowance,

Being able to have a certain amount of fun. Being able to spend it in the way that works best for Sarah. With some restrictions, I use the example of being able to buy the feeding supplies and spoons and I know this isn't a lot of money, but actually along the same order, I bought a couple of writing instruments for her at school because she's having a hard time. She can type her name. She can't write her name, and, you know, they're 12 bucks apiece and so I bought one for home and one for here. That's 25 bucks, but 25 bucks! 25 bucks! (that's a lot of money).

And that's just for her to be able to write her name. I bought a slant board for school. These were like money I'd saved. That's not Medicare Waiver money. That kind of stuff, I could drop a hundred bucks a month, easily on that kind of thing. That's the biggest difference (in having a cash allowance).

In the straight Medicaid plan, too, this is one little conflict I had with them, they were going to buy Sarah a stander, which they won't buy any more. because she has to stand and bear weight. It's very important medically. The stander costs with the Medicaid supplier – they had to get the three quotes, the whole bit—it was \$1800. When I called Ripton directly and ordered it, I ended up paying \$700 for it. And, you know, it's amazing. And the diapers, even the diapers. We got the quote for the diapers. Like for instance, we just switched type of diapers again and I'm putting her in Pull-ups now, but they're big Pullups. They're like the Good Nite ones. But the diapers alone, I can buy them cheaper at Publix now than I can buy them through the same people who've been thru Medicaid, they're like twice as much if I go through Medicaid, even if I buy them in bulk, they're like twice as much. I said forget it. I'll buy them at Publix. Now the other brand I was buying through them because it was the cheapest I could find. I've got almost \$200 a month to spend just on her Boost and her diapers and, I spend it well. I know I'm going to spend \$11.99 to get 18 or 19 diapers at Publix versus \$20 through Medicaid for the same quantity of diapers. It just makes no sense. And if I weren't on CDC, I'd be spending bigger money. I wouldn't be able to go to Publix and buy those diapers. So the cash allowance makes a huge difference.

I feel like we're saving money and we're reaping the savings, with her writing utensils and her slant board. So I've got two now, one for school and one for home.

Mike explains why things cost so much,

One of the things we've learned in our situation is; all the things we need, just because they place a handicap tag on them, the prices are so inflated, it's mindboggling. ... We bought her a chair that sat in a tub, and it consisted of PVC and mesh, something you could go to Home Depot and Lowe's and buy for less than \$30. It came in at \$200. Just for a little thing. The only thing they're not doing is holding a gun on you... You have to have it . . .

For Jennifer,

I would say the monthly cash that comes in to help us with the Boost and the diapers is very, very VERY helpful along with allowing like a family member to be respite care. Otherwise, we wouldn't have respite care and we couldn't tolerate it. That's, I mean, we rely on my mother now, but we wouldn't be able to enjoy it like we do.

(Before the cash allowance) Truthfully, it's not so hard with things that I can buy on a weekly basis because we live paycheck to paycheck, you know? We have a nice home. We worked very hard for it. We don't have a lot of extra money. We bought the Boost at the grocery store. (Before the cash allowance) the things that were difficult (to buy) were like you spend sixty dollars on a slant board and writing instrument for my daughter, just extra things. I needed a shower chair. How do I get a shower chair? A Medicaid Waiver would have bought that, but it's those kinds of things that make it tough, and those are the kinds of things that Medicaid is actually cutting out, the higher dollar equipment things.

(The cash allowance) has really helped immensely because, things can be pretty tight. ... Three and a half years ago, we bought this house, we sold our other house, had it made so the bathroom was accessible. It was as much house as we could afford. We did it for our daughter. And so, we were pretty strapped. And you know, everything that we had was put into our house. Because we did the shower, we did all that because our old house, there was no room to build, she had a little tiny box bedroom. Anyway, we were pretty strapped financially because we were trying to accommodate our child. So CDC came along at a very, very good time, because that was an extra almost \$200 a month and it helped us with supplies, and it's helped us for the last year, and then we had to replace my van. Things like that, ... Medicaid may have done that as well, but it's the time off work, it's the researching, it's a lot. It's a lot.

We actually spend more than that every month, so the \$200 supplements, we put it toward the Boost and the diapers and the wipes, and I also buy chucks for her once, like every three or four months.

Mike describes other items they buy for Sarah, “Most the things we buy for her, like there’s only certain things she’ll eat, like we buy bulk stuff from Sam’s Club like her little fruit cups things.” Jennifer adds, “that’s how our allowance is spent and again, our allowance isn’t even enough to cover that, but it certainly helps.

According to Mike, the cash allowance has helped in other ways, “Well, it, it’s helped and I mean like stress. I mean we don’t stress things, as much as we used to before, when the services weren’t available . . .”

One More Middleman

Jennifer did not have a good experience with the consultant,

Waste of time. One more middleman. I have educated her more than she has done for me... She can’t answer my questions, had horrible training and she honestly doesn’t know the answers. So she keeps making the comment, “Boy, I’m glad you’re doing this first, because now I know,” and, “Where did you say you found that?” because I was telling her. I get Exceptional Parent magazine; most of my friends do... and I’m showing *her* things I’ve seen in the magazine like the features of a hospital bed, “Look at this. This is really good. It looks like a child’s bed, but it has the features of a hospital bed. Have you seen this?” “Well, no I haven’t.” “Well, it’s your job... Waste of time.

I end up calling Paths and asking, okay how do I really do this? And then they end up telling me to call my consultant to get her permission and I’m just... (frustrated). I feel like the better way to do this, and I’m just talking my personal situation . . . I talk directly to Paths and they have some type of authority to say yea or nay, you know, or here’s how you do it or here’s how you don’t do it, whatever and just get rid of the consultant cause she’s no good. And I’ve thought of changing several times but my friends, and I have a couple that are on CDC, say “Mine’s the same way.” “If we get a phone call back in three days, we’re lucky” (Consultants are) difficult to get a hold of, to get a return call. My consultant says “I’m going to bring that paper by and leave it in your mailbox.” Never shows up.

But my friends are having the same problems with their consultants. And they’re in the program as well, so . . . What’s the point of changing (consultants)? At the

point when I was really getting frustrated, because I had several things going that I really needed assistance on, and she (the consultant) was already in the loop. I didn't want to start with somebody new. I just didn't know which would be worse. So I felt, I'm doing it anyway. I might as well just go for it. I basically bypass her as much as I can.

I have no clue (why there's such a problem). And now that she's been in the program longer, she is a little more knowledgeable, but when I really needed the (was) assistance in the beginning. One of the things we did this year was, bought a van, and we put a lift in, a hydraulic lift. That was huge. That was a big deal. We spent, Mike and I spent a lot of time shopping and we got our own consultant--which, I wouldn't expect (our CDC consultant) to know these kinds of things-- to help us shop for a lift. We got the quotes. We did all that. But going through the system, to try to get the money funded, you know, our consultant was no help. None.

The consultant says that she does not spend much time on Sarah's case per month,

There is just a monthly phone call, maybe 30 minutes... Other than a phone call if Mom calls to say that she needs something, I don't really have to give Sarah very much time. Mom controls Sarah, all of Sarah's affairs. And if Mom does contact me to say that she needs something, it's only a phone call away or something, so it still doesn't take very much time. Mom calls me when she needs something or I will just call and ask her how everything is going if I haven't talked to her, and then she will say everything is fine or I need this or I need that.

Like for CDC, she says that she would have problems with receiving funds or they are saying that she can't get this or that, I will call or, and she uses me as a, because pretty much when we get our CDC packet, we go over any savings and what it would be used for, it's all about what we want to use the funds for that we are saving so that we didn't have to go back and re-write everything, so sometimes someone would get a case that they are not familiar or they don't really know what to do, and so I am called in to go in and clarify or just say it's okay, she can do this.

The consultant knows that Sarah's grandmother was the paid family caregiver, but is not sure who the caregiver is at the time of the interview,

I don't even know who she has. I make sure that she is being paid. I don't have any problems getting her funds. As far as selecting who works for Sarah, her mom selects all of that. She does all of that. That's the reason that she wanted to have the CDC Program because she wanted to be in total control.

The consultant feels that Sarah is well cared for, “Mom is very, very, very organized and very professional and articulate, and I think that she is going to make sure that Sarah gets the best services available for her. She is doing exactly what she is supposed to do with the funds.”

Problems with the CDC Program

Jennifer describes some accounting problems that she has had with the program since the beginning,

In the beginning, we got a financial statement every month, but it wasn't very easy to read and I'm an accountant and I can read financial statements. However, I found some errors on them, and one thing they do that I don't think they should do is send me a November statement but the beginning balance won't agree to the ending balance in the October statement so it's like they went back and changed the October without giving me a new October one. Well that does me no good, because I can't see what's going on and I feel like they should change their format, which they did recently.

Now I've got to be honest with you the last statement they sent me, I haven't looked at yet because we've been on vacation. I just haven't looked at it. So maybe it's A-okay. But my Excel spread sheet does not match their statement. And I know my Excel spread sheet is right... So I called them and I said, “Okay, how do I read this?” Because I want to know. “All I want to know from you now is how much money do I have left to spend at the end of this month, per your records?” Because I want to know how much savings I have to spend. You know. How much is left? Well, they were able to tell me. I spoke with someone very knowledgeable there. “Here's the line I you to look at.” I have no idea where they got that number, but it was close to mine... Because I want to use some extra respite money. I've gotten other people's checks in the mail. When we got our check for our van, what was it? An \$8,000 check, I got two of those, two \$8,000 checks made payable to the same vendor. I called them back and I said please void this and make sure it doesn't appear on Sarah's financial statement.

I think the program is very good, but it's been difficult in dealing with. Well one other thing, I don't know the other issue that I have with it is that the consultant seems to have the final say in what you can do and what you can't do. And my friends, we talk (about what consultants do), which is probably the consultant's worst problem. The consultants have different rules. And one consultant may say “Yea, that's good, we'll do this under this category,” or whatever and another consultant may say “Well, no, no way. You can't do that” But if she says, “No, no

you can't do that, that person's going to quit that consultant and go to the more lenient one. So, that's the way it works. I mean right now, I have a name of one consultant who is doing really well and really fighting hard for the people that she's representing. So everybody wants her because you can get more stuff. That's the bottom line.

Most of the "stuff" that people are asking for is legitimate, good stuff that we need but, there is too much gray. There's no consistency and that's another problem with the program.... Most of the time, it's necessity, whether or not they consider it frivolous. I mean the plates that I was buying were not, you know Mikasa. I hate to tell you, they're pretty ugly. Not like I *want* them. I *need* them and the other thing is the inconsistency . . The inconsistency between what one person gets versus what the next person gets because they have a different consultant or because they hit somebody in a different mood should not be. For instance if they said, "Okay, you have \$1000 for nutritional evaluation." If I don't want to spend that money on a nutritional evaluation or if I save \$300 on my nutritional evaluation, I feel like I should be able to buy pretty much anything I want with that, as long as it's for the betterment of Sarah, but as long as it's something for her, I don't see the harm in that.

According to the consultant, there were some start-up problems for Jennifer and Mike,

We had some problems with getting her; I can't remember right now. It wasn't a major problem; it was trying to get Sarah started up on the first of one month, and we missed the deadline because we didn't have, I can't even remember what it was; I think it had something to do with her insurance ... so we had some problems with that initially, just getting the documentation that was requested, getting it approved and all that, but nothing major.

About a month ago, she attempted to purchase something with the savings and they told her she couldn't. I called them and we got it cleared up and that was it. As far as I know, I called Mom and told her what I did and what was said and I haven't heard back from Mom or the CDC office, so I'm assuming that everything went smoothly.

Benefits of the CDC Program

The CDC Program has been a great help to the Sullivans. Jennifer describes the advantages,

It's helped immensely in providing some services that we wouldn't have gotten otherwise. I mean, Medicaid flat-out wouldn't give us the therapy for Sarah. That's the most important thing to us, because, we both are offered health insurance through our employers and neither one those insurance companies

would give her therapy. That's very important to us, a Medicaid waiver would do that without CDC, I understand, but there are some things like the daily cost of her Boost, her diapers, I mean, like we're spending like \$4 a day in just Boost for this child.

And she doesn't eat well, so that's sometimes that's all she eats. We have to have that. And the diapers, now that she's older, I can't buy them at the grocery store any more and they're 75 cents apiece. So, they're very expensive. So that has helped immensely. The other thing is the respite care. I can't tell you how nice it is to have respite care. We just now are at the point with Sarah that she will allow us to leave her for any length of time, so you know, a movie was unheard of. We're just now at the point that we can enjoy that. That is a tremendous help to us. The other thing is just allowing us the flexibility, for instance, I had some nutritional money that I could spend. I didn't spend it all, I was able to use the balance to buy some larger plates for her . . . some spoons . . . things that for nutrition, that actually the nutritionist has recommended for her to get her away from the baby stuff. She doesn't need to be eating out of a baby bowl anymore. She needs a nice plate. You know, they're *expensive*. So, we're able to use the money for things that I don't think we could have done otherwise, or at least not as easily.

I'd encourage the CDC program definitely, because it has enabled us to do more for her and get more for her spending the same dollars that otherwise might be wasted because we're overpaying other people.

Consumer Story 13

Adam Connolly is a 26 year-old white single male with Cerebral Palsy who lives with his parents in a home in rural Florida. His mother Nancy is his representative. Adam attends an adult day care center for adults with disabilities north of the Miami area. He attends the center five days a week from 9 a.m. until 3 p.m. The center was clean and spacious. Adam and his mother were interviewed in one of the physical therapy rooms. Adam was in a wheelchair, was very friendly and welcomed the interview and the questions. Nancy engaged Adam in the interview and he was able to answer some of the questions. Adam and his mother seemed to have a strong bond and were loving and playful throughout the interview. Diane, who is the Executive Director of the Center, was interviewed as the non-family caregiver because Adam receives assistance at the center during the day. There are six staff members at the center for fourteen participants. Adam's parents take care of him at home after he leaves the center and on the weekends. Adam has two brothers, one his twin, who have left home. The Connolly family is very close and Adam's parents include him in all their activities.

Enrolling in the Program

Nancy said that they decided to enroll in the program because it sounded very appealing to be able to hire people that they already knew and trusted to care for Adam. They were also interested in the flexibility of the program.

I Don't Have Seizures Anymore

Nancy describes Adam's condition, "Cerebral palsy is the main issue. He was one of a set of twins, and his twin brother is fine and never has been a problem, but..." Nancy is surprised when Adam adds, "He was lucky." She says,

That's the first time I've ever heard him say anything. And then what happened, seizures like crazy. He contracted viral encephalitis back when he was eight years old, and that's what started a lot of the physical and therefore mental (cognitive) problems, the seizure activity knocked him down.

In the last three years Adam has been on medication that controls his seizures and has been able to make huge strides in his physical and speech therapy. When asked what he needs help with Adam says, "I don't have seizures anymore." Nancy describes the change, "What a difference. There were a lot of years with a lot of seizures and it has been three years now with no seizures. It's absolutely incredible. Big change, huh?" Adam adds, "No stupid wheelchair." At a question from his mother Adam adds that he hated his red wheelchair because of the harness.

Nancy describes how Adam's life is changing,

(He has) a whole new life. (He's) out of the wheelchair now and he has been up and walking around as best as he can. We still have a power chair for him, but with the seizures (before) he couldn't even begin to do a power chair on his own.

Diane has also seen the transformation in Adam since his seizures have been controlled,

Adam's needs are much smaller than most people (with cerebral palsy) who typically don't have language and their physical disabilities are far greater. Adam continues to improve. His Mom works a lot with him and so the fact that he could take those few steps is amazing, he used to be in a power wheelchair. (His progress comes from) the success of his Mom and just constantly talking with the neurologist about some of his medications and he was just on a wrong regime before. What we thought was immaturity (was that) his medication was really out of whack for his seizures. He had seizures frequently and he had a really hard time focusing. So when I first met Adam I just thought that's the way his personality was. His Mom really, really stuck with one neurologist and when she wasn't getting anywhere she would go to another neurologist and since they changed his medication he has just blossomed. Things that he just couldn't remember before because he was so overdosed on some medications (he can remember now). That's why he works so hard on academics that he retains it. It's not like this futile effort... He's really making great, great progress.

Previous Experience

Adam's family provided all of his care which was physically demanding until Adam's recent improvement. Growing up, his brother's helped their parents with Adam's toileting and bathing. Adam attended a daycare center, but according to his mother it was difficult to find a center that fit his needs,

Adam has been tough to place a lot of times because of the fact that he has both mental and physical disabilities, so he could either be good in one area and lousy in the other and it has been hard to find a place that is a great center for him.

Because of Seizures We Lost a Lot of Time

Now that Adam is improving so rapidly Nancy feels that they are making up for lost time. Adam needs to work on academic goals, interaction with his peers and physical and speech therapy. Outside of the center, Adam's parents take him wherever they go. When Adam was still having seizures he slept through everything. Now he interacts with everyone.

Diane explains that in the center Adam needs to work on basic academic skills like writing his name and working on money skills so he can go to the bank and stores in the shopping center to practice. Adam is learning simple food preparation skills and is also working on the computer learning basic Internet skills. Diane and the center staff also take Adam on outings in the community to the library or to the zoo, or anyplace that he finds interesting. Diane elaborates on Adam's needs,

He needs assistance with just blocking in general, anything bigger than a nut. He needs a lot of physical hands on help. (Adam needs) minimal assistance toileting, minimal assistance with lunch, and setting up. He can feed himself, but just needs some help with wiping and cleaning up and certainly, at this point, maximum assistance with his academics which is what we focus most of our attention on. And then a good chunk of the community integration things that we do certainly requires one-on-one (assistance). He is not near ready to go out in the community

by himself. He needs somebody to get on and off the bus with him and talk to him about where are we in relation to the Center.

Adam is able to meet his therapists at the center. Nancy explains that they live “kind of far out,” so it would be a “massive” job to take him to the therapists.

Occasionally Adam needs help with toileting which the staff at the center will help with, When we were looking for centers for awhile, that was an issue. If he needed any cleanup from toileting or whatever, they wouldn't do it, and so that knocked him out. There (can be) a hard little thing (like that) and you can fall between the cracks.

The Importance of Flexibility in the Schedule

Adam attends the center from 9 a.m. until 3 p.m. He eats breakfast at home and lunch at the center. Nancy says that after he leaves the center,

Then (he goes) home. He does have horseback riding. Before (the program) they would not allow that as physical therapy, and I can include that as physical therapy (now). He loves that and that enables him to be in the Special Olympics. Winning ribbons and going to Tampa even for the state games.

Caregiver Relationship and the Qualities of a Good Caregiver

Adam's mother supervises Adam's care. She brought Adam to the center because of Diane,

She's non-family, but came to know her and trust her through the other center. Then as he progressed and we had that flexibility to be able to come here (because) we liked her leadership. We liked what she did. We liked the program that she was starting up, and we were able to come here.

Nancy has a clear idea about what makes a good caregiver,

First of all their ability to interact and show just by their interaction that they value those with disabilities, and their professionalism, too. But I guess their consistency and I would have to say integrity, too. I certainly want to mention that. And certainly again the ability to know that everything is above board, that there aren't any immoral, unlawful things that are going on.

Diane says that she and her Center are monitored and supervised by the state. She describes her relationship with Adam as being very good because he is very happy and

willing to participate at the center. Diane says that she and the center staff have to work with him on advocacy issues because as a young person still living at home he is, "... still in that mindset of Mom makes all my decisions." It also makes Diane feel good to see how much Adam is improving.

Other Uses of the Cash Allowance

Nancy uses some of the cash allowance to hire a couple who were teachers at Adam's previous Center for occasional respite care. She considers it to be a real benefit to be able to hire people she knows and trusts to care for her son.

Nancy and her husband bought a van to transport Adam out of their own pocket. Nancy finds other uses for the cash allowance including the costs associated with the power wheelchair and a small amount spent on entertainment for Adam,

He loves videos, so that's what it ends up supplying. It used to be diapers and things like that. Now that the family dynamics have changed (with Adam's physical improvement), we don't need a van other than for him specifically, so we are saving for the maintenance of the van because like when we go to church or whatever, he wants to be in that power chair so that he can motor his way around and all. So we still see (the van) as a need, but it wouldn't be there if it weren't for (the cash allowance). So he's using (the money) for maintenance, and my husband saves a good amount on maintenance by doing things ourselves, but there are some (repairs) that are beyond us.

The Role of the Representative

Nancy describes what she does as Adam's representative,

Basically, tracking down everything. So far, even with the transportation, I have been trying to find companies. I have also been on the phone, making sure that I get all the book work from everybody, all the invoices, getting all the prescriptions and getting all that kind of stuff, too, to be able to have the physical therapy and all. The phone calls are time-consumers. It's amazing. We should order a secretary for him at times, but again, with that flexibility (in the program), I'm willing to do that.

(I also) keep his life in order when it comes to the paid invoices so that we can keep him in the Center or that the therapists aren't dropping him because they are

not getting paid. (I have to) know his personality and know the people that he is working with... There were several times that we ended up backing out (of care arrangements) because we just did not feel comfortable with the situation. I'm not going to risk it for him, I'm just not.

How Effective is the Consultant?

Nancy thinks that Adam's consultant, Cindy, wants to do the best for her son, but she is not sure how effective she is in helping her family receive the services they need.

According to Nancy, Cindy has been helpful,

She knows her stuff, and I am comfortable with her. However, under this program, I feel like I am doing the major part of the work, which I don't mind, and if I got that kind of flexibility, I'm willing to do that, but to have that chunk of money coming out and going to a consultant, I don't know.... (When) I was making this budget and making it come in line with the money, and they kept saying, no you are over budget. And I would say, what? Why? What it was is that we did not factor in her amount, so all of my other categories were higher than what they should have been because I didn't know that I had to pull the money or withhold the money, you know, for Cindy to be able to get it. So I know there is something going out, and I want to say it's around \$1,600 per year or something like that, but I might be off. I think that seems to me what I had to pull.

Nancy says that Cindy is good about calling her back. Cindy does a variety of tasks for them,

She keeps all of the paperwork. Obviously, not the financial part of it. I'm doing that, but I don't know what the state all requires book-wise, so I guess there she is sort of in charge. Transportation has been a tough issue for us; finding somebody. I don't think that we are that far out, but obviously a lot of these transport companies do not want to deal with a mile on the dirt road, so we just have had real struggles, and she has tried. From what I understand, she tries hard, but, you know, she is coming up dry a lot of times. So right now I am transporting Adam again, and I'm not getting paid for that, but I'm transporting him, and if that's what works to be able to still bring him here, I will go ahead. But I don't know how effective Cindy is behind the scenes.

Diane feels that Cindy has not been helpful or assertive enough in helping Adam and his family. Diane thinks that the two other Consumer Directed Care consumers at the Center have better and more accessible Support Coordinators than Cindy. Diane thinks

that part of the problem may be a lack of knowledge about the CDC and a hands-off attitude to former clients who are now consumers in the CDC program.

Problems with the Program

Nancy has had a difficult time arranging for consistent transportation for Adam. Nancy is driving him to the Center herself after receiving only two days notice that the transport company would no longer take Adam. Nancy says that having transport for Adam would help her, “but life is not about being easy.... Sometimes it’s just easier to transport yourself than to mess with some of the aggravations.”

Nancy also has problems when providers, especially transport, do not understand the concept of consumer direction and call the Support Coordinator for authorization for their services, not understanding that Adam is paying them.

Nancy is not sure that she is correct about the arrangements, but she is concerned that consultants receive the same amount of money from the program than they did before consumer direction,

As a parent, I don’t want it to be a paid position for me. However, there are times where it becomes time consuming and demanding on me as a parent and representative. I don’t know how that balances out. I don’t know. I don’t feel that the consultant should earn as much as what they get prior to this program... Maybe they don’t make as much as what they used to. I thought they still do, but I don’t know that. If they do, then it’s wrong that they make the same amount.

I can see where the consultant is necessary, too, because they should be the resource of knowing what transportation companies, what physical therapists, what people are out there that they have used that they would be familiar with (as a resource for families)

Nancy thinks that the parents and representatives should receive budget training,

As a brand new rep, I know there was training for the consultants. However, there was not for a parent or representative, and I think that there ought to be. I think that there ought to be, whether it is a workshop or a class or something like that, where we can come when we were starting out, with our budget and sit right

there with the big guys who are either going to approve it or whatever, ask the questions, work through it, and get it done that day. That was a horrible frustration for me starting out because by the time that the rule got to one person to the next person and then to me, it had been misunderstood, and the amount of phone calls and refiguring and time-consuming on that was absolutely unnecessary and aggravating. So if we could go to the real source, that would be fine, but to do that authority structure was frustrating, so I would highly suggest that there be a workshop for a parent just beginning on that budgeting...

Nancy has had a few problems with the Fiscal Intermediary losing paperwork and “screw-ups” in cutting checks. Nancy feels that the staff are trying to do a good job, though,

I have never had a rude person. They have always been very pleasant trying to help and trying to understand... At least I’m dealing with people who act professionally and are pleasant and courteous, so that is a huge help. I mean it’s overwhelming for them, too...

Diane thinks that it is difficult to increase services for a consumer once they are in the program. Using Adam and several other program consumers as examples, Diane thinks that if a consumer starts in the program without therapy in their care plan it will be very difficult for them to add it later.

Benefits of the Program

Nancy says that she would recommend the program to another parent. Program participation benefits Adam and his parents,

First of all, it gives us a break. I mean physically before we found this and there was some time there when I knew the kids (her sons) were leaving and there was not going to be any help and he was so physically bad, I didn’t spend a whole lot of time worrying about it, but it certainly was a factor when he was home for awhile. It gives us a break, but then it also gives Adam the opportunity for interaction and then continues to bring that home and he is real active in anything wherever we go to church or with community events or whatever, he is always with us, so it is kind of neat even when he has gone with “his” friends and “his” world.

Before the program Nancy feels that her family was very limited,

We did not use the respite. We don't abuse it, now, I mean it is not a huge thing because I do have some family that lives an hour and a half away that could help in major situations, most of the time, but (respite is) huge. Again with the physical therapy, with the horses, with the success that he sees in himself there and the horseback riding, and then just the ability to interact with people (those are the benefits of the program).

Nancy likes the flexibility of the program,

It does make life easier for me to be able to consolidate the location of therapy (at the Center)... I feel that Adam's in better health and a better mindset since we have those choices, too... I think things have gone much smoother because we do know what's going on. Again, the option to get out and to have a break, which we didn't take before, and that's a huge thing to my mental well-being, mentally and physically for me as the representative, but also as his mom.

Nancy asks Adam to add anything else he wants to say, but he is getting tired and so the interview ends.

Consumer Story 14

Mrs. Nora Bennett is a 98 year-old white widow who lives with her granddaughter and her granddaughter's husband in a middle class neighborhood in suburban Florida. Mrs. Bennett is a widow and describes herself as being "as old as I feel." Mrs. Bennett has mild dementia and vision problems. Her granddaughter, Mary Beth, is her representative and she has a non-family careworker, Sylvia, who worked for her as an agency worker before the Consumer Directed Care Program started. The house was very clean and elegantly decorated. At the time of the interview, Mrs. Bennett, who was clean and well-groomed, was sitting on a recliner watching television. She cried a little when she saw that somebody had come to visit and talk to her. During the interview with her representative, Mrs. Bennett became concerned because she was afraid she would be asked to sign something, "I did that once and I got into a lot of trouble signing, I ain't going to do it anymore." Mary Beth patiently explained the purpose of the interview. Beth answered most of the questions, with participation from her grandmother.

Being 98 and a Half

Mary Beth says that her grandmother's only problem is being 98 and a half. Mrs. Bennett takes blood pressure medication which she has been on for 30 years, but otherwise takes no medication. She needs someone to be with her at all times.

Enrolling in the Program

Mary Beth heard about the program through her grandmother's case worker. She said that she was interested in the program when she heard that she would be in charge of how the money is spent and the caregiving hours, "I didn't need too much convincing

after that.” Mrs. Bennett also had an agency careworker who was willing to be hired privately, “Had Sylvia not been with me, I’m not sure I would have jumped that fast.”

Previous Experience

Mary Beth has cared for her grandmother for 7 years. She and her husband brought Mrs. Bennett into their home two years previously because she could no longer be left alone. Before enrolling in the program Mary Beth relied on family members to come and help occasionally. Once a year she would pay a niece and a sister to stay and care for Mrs. Bennett while they took a vacation. Three weeks prior to the interview one of Mary Beth’s 18 year old nieces had moved in to help with Mrs. Bennett in exchange for room and board. The family also had agency workers come to help Mrs. Bennett. Mary Beth did not like having, “... 2 or 3 different people in my house all the time, which was what was happening....., at one point there was a different person in every single day for two weeks.” The agency worker’s hours were also not useful for the family. Agency workers came from 8 a.m. until 2 p.m. even though Mrs. Bennett does not get up until 10 a.m. Mary Beth said that workers were being paid to sit. She also did not like different workers providing her grandmother with personal care like bathing because she felt that this was unfair to a woman in her nineties who grew up with strong ideas of privacy. Mary Beth describes how they worked with the agency,

We just did what we could. I had to work the schedule that the agencies gave me. It wasn’t pick and choose. They said “This is the hour, you’re entitled to these many hours, we give you somebody three times a week, eight hours a day.” I don’t need anybody three days a week, eight hours a day. I need somebody spread out for the period of time that my grandmother’s active. That was a nightmare, but that was the only thing available.... There was a period of about a year before Sylvia came to us, about six months maybe before the program became available. The year prior to that I almost lost my business and everything because agency workers never showed up, it was different workers and it was awful.

Needing Help with Everything

Mary Beth says that her grandmother needs help with “everything—well, she can go to the bathroom by herself... getting dressed, shower, fed, when I’m not here, we don’t allow her in the kitchen.”

Daily Caregiving Tasks

Mary Beth does many things for her grandmother, “everyday living things. I don’t bathe her, I do take her to the bathroom, feed her, do the normal things, we get her hair dyed, we have a family reunion by the end of August, so she gets to see great, great, great, greats, four generations, five generations.”

Mary Beth describes what Sylvia does for Mrs. Bennett every day,

She comes in, gets her up in the morning, wakes her up, gets her breakfast, then she brings her in here and they will watch TV, or read the newspaper together, because she’s very interactive with Grandma. Sylvia usually gets her up around 12:30 or 1 o’clock to go in and have her shower, gets her cleaned up from there, then they have lunch, do whatever else, watch TV, there’s not too much you can do.

Sylvia cooks for Mrs. Bennett. Mrs. Bennett is able to feed herself. Mary Beth thinks that the most important thing that Sylvia does for her grandmother is,

Keeping her clean, ‘cause I can’t do it, I have a bad back. That’s what prompted everything to begin with (Mrs. Bennett had a fall in the bathtub) and I had a bad back at that time, so it was time for us to bring somebody in the house. The back is usually the first thing that goes, isn’t it?

Mrs. Bennett says of Sylvia, “She’s very sweet, she’s a good lady. She does a lot of things for me, she gets me a shower, she takes care of me, very good in every way, she does nice work.”

Sylvia sums up her work with Mrs. Bennett, “Breakfast, shower, lunch, exercise, and then I go home.” She elaborates on what she does,

I do it all for her. She cannot do it herself at all. I give her the shower. I do her peri-care.... and if she is not cleaned thoroughly she gets sore. She moves her bowels and urinates and walks to the bathroom by herself, but she is not too good at cleaning herself.

Sylvia helps her dress,

She has to be helped. She gets confused, and she can't see. She says she doesn't (have trouble with her vision), but she can't see anything. Mary Beth does her hair. I do her nails. I take her for shots when she needs to go. If Mary Beth is busy working, I take her to the doctors. It's around the corner. She only goes once a year.

Careworker Schedule, Supervision, and Pay

Mary Beth says that Sylvia works, "Four days a week, six hours a day" and her schedule is,

Whatever mine is. I am in my home one day a week because I have phone calls (to make), and filing, and everything, so, whatever day that I'm home I won't have her come. She's here today only because you (the interviewers) were coming. The rest of the day would be her off day. (When she comes) she's here from 10:30 to 4:30 or 10:00 to 4:00, something like that.

When Sylvia doesn't come to work it's "My niece, or myself, or my husband" who stay at home with Mrs. Bennett.

Sylvia says that she works from 10:30 in the morning until 4:00 in the afternoon, "I get widow social security, so I try to keep it to like 23 hours a week. So it's good for her and good for me." Sylvia describes the schedule from the time she arrives,

Like I just arrived here at 10:30 this morning. I get her out of bed. I put a robe on her and get her out of bed. I take her out in the kitchen. I make her breakfast. After breakfast, we usually go in and sit for a few minutes and talk on the couch for a half an hour or so and watch a little TV. Then I try to get her up and get her in the shower. It takes me about an hour to do that. I bring her back out. I do her lotions and her hair and all that. I bring her back out. I give her the snack. I put her on the couch. I put her feet up like I have them. She watches TV or listens to it, and then I do her bedroom and I do the bathrooms. Then I go back out and we get lunch. Then I will toilet her, well try because she is stubborn sometimes. But that's a typical day. By then it is 4:00 and time for me to go to my other job (laughs). You can't hurry her. She's an older, slower lady. I clean all my

messes. I do all the dishes and everything that I use. I take care of everything. I try to keep it neat here.

Sylvia says that she decides what to do based on her experience as an L.P.N.

Mary Beth pays Sylvia \$9 dollars an hour. Mary Beth explains that Sylvia first worked for them through an agency, but then when she switched to hiring Sylvia directly through the program, it gave them,

the ability to offer more dollars per hour. She (Sylvia) said, "That's fine because what you are making up I can just work this one job instead of having to work 2, with two different people and schedule the hours differently." So, rather than make \$7.50 an hour (she makes) \$9 an hour. That extra \$1.50 an hour made up the other hours that she had to do some place else. So it worked out perfectly for us.

Mary Beth says that because she is her grandmother's representative, she manages and supervises Sylvia.

Use of the Cash Allowance

Most of the cash allowance is used to pay Sylvia's salary. Mary Beth describes other uses of the money,

We have Sylvia's salary (in the cash plan), which gets paid and then we put it into our plan that twice a year we would take "x" amount of dollars – because we'll be going away for (a vacation). We will be ready (to go) again somewhere around October. We (Mary Beth and her husband) will probably take off for 5 days. So we take, I think it's \$500 or \$600 and we'll use that to pay for other caregivers to come in and take care of my grandmother. (We can use the money for respite care because) she doesn't take any medicine, her medicine costs \$5 every 3 months.

Mary Beth needs to buy basic items for her grandmother,

Hygiene and grooming items, her food has to be soft. The things that she likes to drink, juice and chocolate milk and so basically that stuff or clothing; slippers, her hair dye, no Depends (incontinence care items) or that stuff yet.

The Caregiver Relationship; I Miss You Lady

Sylvia and Mrs. Bennett have a close, friendly relationship. Mrs. Bennett says of Sylvia, "I'm very happy with her. I wouldn't change her for nobody else. She is a very nice lady." Mrs. Bennett describes what Sylvia says after not seeing her over the weekend,

I missed her and she missed me too. She told me when we were at the party, she said, you know, she calls me 'lady' – you know lady, I miss you a lot. I said don't say you miss me, because here we are, where we are. We have a nice time here.

Mary Beth thinks very highly of Sylvia,

My family absolutely adores her and trusts her with everything. She has a key to the house. She knows where all the important documentation regarding her is kept. It's a very, very good situation right now, and it's all because of the program, it really is.

Sylvia has cared for Mrs. Bennett for 3 years. Sylvia describes her relationship with Mrs. Bennett,

It's kind of like very friendly and she misses me so bad when I'm not here. She tells everybody. She gives everybody a hard time when I'm around. Remember, she calls me "Lavinia." Or "my girl." We have a very good relationship.... It's just so nice and relaxing and comforting to be here. She's a lovely, lovely person. I listen to her stories.

Sylvia has not had any conflicts with Mrs. Bennett, "She gets a little agitated when she has to go in the shower, but that's normal. But we usually sing and tell jokes, and she forgets about it."

Sylvia knows Mrs. Bennett's family and gets along with everyone. She is especially impressed with Mary Beth who she describes as one of the best caregivers she has ever worked for. Mary Beth calls Sylvia two or three times a day to check on her grandmother.

Caregiver Experience

Sylvia is an L.P.N. and began working for Mrs. Bennett as an agency worker,

I have been in the nursing business since 1958. I have worked in Alzheimer's wards. I've been a head nurse, and right now I'm working in assisted care in a nursing home. I've had lots of training.

Qualities of a Caregiver

Mary Beth says that what she looks for in a caregiver is, "Honesty, caring and stability, they are going to be there. Dependable, they have to like what they are doing."

Sylvia describes the qualities of a good caregiver,

Somebody that's not lazy, somebody that is conscientious, somebody that's careful, somebody that's concerned. I mean it's more client than it is money. A lot of the girls it's money and to heck with the clients.

The Advantages of a Non-Family over a Family Caregiver

When asked if she thought it was better to have a family or non-family caregiver, Mary Beth clearly preferred a non-family caregiver,

Wrong can of worms to open with me. Given the given situation we are in I prefer the non-family member. The family members do it when it has to be done, but that's it. Family members have expectations, like can't you do this, don't do it this way. Non-family members don't have any expectations. They just treat the person accordingly.

Comparison of Work for an Agency and the Consumer Directed Care Program

Sylvia prefers working for a consumer in the program over agency work because she feels that she can do a better job,

When I worked for the agency, I was given a specific day to come in and just shower Mrs. Bennett and then specifically just to come in and sit with her. Now when I come in, I shower her daily, and I can take my time. I don't have to worry about getting in and out of here in 45 minutes to an hour for a shower. That's the only change, really. When you work for an agency, you have a limited amount of time to do things, and you really can't do them. I don't think you can do an excellent job when you do it like that. I feel like I am doing a much better job

now than having to come in fast and get it down and when you go down the road and say I should have done this and I should have done that. I'm happy. It's better pay. I'm more relaxed. I don't have to worry about getting a phone call every 15 minutes to go here and go there. I still go down to the Agency and see the girls who I used to work with.

In addition, Sylvia feels that the job is friendlier,

There is more appreciation for the work that is done (for an individual consumer). It's a friendlier atmosphere. It's the people, the person that I'm working for, Mary Beth and her husband and Nora. Nora is such a beautiful person. It's an easy job to do. It's like being in my own family. Scheduling is no problem because it is a phone call away. I feel like Mary Beth is a friend and she feels like I am a friend. She can pick up the phone at any time. If she doesn't need me, I don't come. If she needs me the next day earlier, I come. You know, it's a very relaxed thing that we have. I have always had an "on the schedule" all of my life until the past year on this program. It has calmed me down and freed me up. This is what I try to tell the girls (at the agency) because you know when you run in a regular job and you are working from an agency, your life is going just like this all of the time. When you have a family, you have to go to this and go to that. (Other agency workers) figure the more jobs they do for an agency, the more money they are going to make and the more hours they are putting in. It always doesn't happen that way. (They burn out).

Contact with the Consultant

Mary Beth says that her consultant calls regularly to see if her grandmother is doing well on the program, but,

I'm one of her easiest clients because it is working so well for us, that there is not a whole lot of follow up to have to do. Now that could change, obviously, if we lost Sylvia, but we are really so self contained and on such a good schedule now that our consultant doesn't have to do a whole lot.

Problems with the Program

Mary Beth has not had any problems with the program other than occasionally going over the caregiving hours. She feels that the communication with her consultant and the fiscal intermediary is good and when there are problems they are handled quickly and efficiently.

Benefits of the Program

Mary Beth feels that the program has helped her family in their care of Mrs. Bennett. Mary Beth says that this program has helped her care for her grandmother at home.

Flexibility is a key. I'm in sales so I don't go to work Monday through Friday. Tomorrow I'm gone from 6:30 until midnight and the same thing on Wednesday. So, consequently, my niece will be here in the morning and Sylvia will come in, and when she leaves, my niece will be here.

Consumer Story 15

Ms. Julia Lynch is a single 89 year-old African American woman who lives alone in a one bedroom apartment. Her apartment is part of a low rise independent living complex in an economically depressed suburb of Miami. She was interviewed with her daughter Karen who is also her care worker. Karen lives about 5 minutes away from her mother. The apartment was small but neatly kept. There were numerous Christian religious hangings on the walls along with many family photos. Ms. Lynch, who wore a housecoat and appeared unkempt, seemed tired and dozed throughout the interview. Her daughter assisted in answering questions. Ms. Lynch and her family have few resources and are presently involved in a dispute with the landlord who wants to evict Ms. Lynch because of her incontinence.

Medical Condition

Ms. Lynch is diabetic and incontinent. Karen tests her blood sugar every morning and puts out the medication for her mother to take. Karen also accompanies her mother to her doctor's appointments and keeps in close contact with the doctor about her mother's condition and medical needs. Karen says that her mother is recently complaining of pain and has difficulty getting around.

Enrollment in the Program: Having Trouble with Helpers

Karen says that she and her mother heard about the CDC program through the state consultant. Ms. Lynch was especially interested in the program because of her problems hiring good helpers. Karen explained why she and her mother thought the program sounded good,

... She has been having trouble with helpers that the agency used to send... one girl had pushed her down and almost broke her hip. She was in such agony and

pain and she never got as strong (after that) and then when this (program) came along, it was like an answer to a prayer because the consultant let us know (that) if she gets help, they will pay for it. They will help her with little stuff, personal stuff, underwear and chucks if she uses them. We could be able to afford to buy them through (the program), and so we said okay, we will give it a try.

Ms. Lynch describes the problem she had with a previous agency worker, “She gave me one push and I was down. I’m a skinny person and I was gone.” Julia describes how the woman stepped over her into the room while she held on to her skirt trying to fight, “The girl came in and stepped over me and took my money from the other side of the room.”

Karen adds,

I was busy out and so I didn’t know about it until everything was done. We took her to the hospital. I didn’t know about it until it was all over... The agency did not cooperate. They are out of business now anyway because they would send more than one misbehaved person.

Julia never wants to hire an agency worker again,

They are not nice and they will do anything. I don’t want them. I won’t even sit in the room and give them a drink of water. They are deadly enemies.

She Likes to Be Independent

Julia describes what Karen does for her, “She washes and she cleans up the house. She washes the dishes...and everything else. Karen describes what she does,

When I’m here, I do everything. When I’m not here she putts around and does her little stuff. She likes to cook her stuff and sometimes when I make it for her she’s picky, but she likes (to be) independent, and she likes to do her stuff. Right now, it is a health issue that she is having, which she is having lots of pain. She is not getting a lot of relief from it and so I help her with everything....her laundry, straightening up the house, vacuuming, cleaning and stuff like that.

Karen helps her mother prepare meals,

When I’m not here, she does it. (My mother) does her baths when I’m not here... She just showers herself until I get here, and I will do the hair and so on. She did

(her hair) this morning, so it is a little messy, but she does a lot of (her own) personal stuff.

Julia says that the most important thing her daughter does for her is wash her clothes.

Karen explains why this is important to her mother,

I am going to elaborate on that a little bit because sometimes she's incontinent and I know it is embarrassing for strangers to come, but I am her daughter, and I see these things. I just pick them up and then take care of them, so I think that is probably why she said that.

Karen helps her mother shop for groceries. She continues to list some of the other things she does to help her mother,

I always work my way around (the apartment). I come in here and do all sorts of things in the kitchen. Clean the refrigerator, empty the garbage, everything. And bathing her as well as doing her hair. Lots of times she does it herself. I don't want to make her helpless, so she does it sometimes.

Schedule and Pay

Karen gets paid for 19 hours a week at \$13 an hour. Karen works 5 days a week, approximately three hours in the morning and 2 hours in the afternoon. She says that she regularly works more hours,

I go over it all of the time, but, if I was getting a million dollars, it would not help balance out being with my mother... I do what I have to do, and if I get a little (money) along the way, it encourages me.

Karen says that if she was working full time it would be more than 5 hours a day anyway so she does not mind staying longer for her mother and she regards the pay as a nice cushion.

I think I'll use the word "blessed." I'm blessed to be getting something to do it, because it's my mom. But, you know, not realizing that somebody would pay me to do my mom, so I'm enjoying it both ways, so it is a blessing. (I'm happy to do it) whether or not you are giving me anything.

Supervision

Karen says that she supervises herself, but she describes how she works with her mother, "...if it's necessary, I just bring it up. I say, "mom, consider doing this" and she goes along with me if it's necessary to be done at the time."

Use of the Cash Allowance

In addition to Karen's pay, Julia pays for one day a week in daycare which Medicaid did not cover. Julia must also pay \$5 a day for transportation to daycare. Julia is also saving to buy a microwave for heating food. Julia used to get Meals on Wheels, but on the CDC program she would have to pay for it herself so she decided to cut it out, "I have so many things to pay for. I can't pay for everything."

According to Julia's consultant, daycare has made a big impact in Julia's life,

Miss Julia is a good candidate for the project. Miss Julia was a very, very angry, despondent, depressed person when I met her. Now that she's able to go to adult daycare during the day she's a whole different person, but without that project they wouldn't have been able to afford for her to go there... When I first met her, she wouldn't talk with me. She was bitter, she was angry and we was just trying to think of something (to help her), and her daughter takes very good care of her, but Julia was saying that she wasn't, and we was just trying to decide what could make a change in her and they read the manual and she saw adult daycare. So I personally didn't think that Julia would do well in adult daycare. I was very reluctant to put it on the purchase plan, so I said well, we'll just try for one day to see if she would like it. I did my follow-up with them on Monday and she had me laughing so hard, how happy her mom is just going that one day to the adult daycare.

Karen also buys Pampers and pads for the bed from the cash allowance.

Being a Representative

Karen describes what she does for her mother as a representative,

Paperwork type of things, I do her banking business for her. We go shopping, and if she needs underwear and that kind of stuff, I will get them for her. So, the private stuff I think is so important that even though she is a case worker or if she is somebody you can talk with, you (would still) kind of feel bashful telling her those things.

Karen feels that she can do things for her mother that would be embarrassing to have a non-family member do. Karen also feels that her mother does not understand all the ramifications of the program and needs her help to get all the services she needs.

A Mother Daughter Relationship

Karen laughs when asked about her relationship with her mother,

We fight all the time, but we have good times! We disagree, but agree after, so it's okay. Like an old marriage! Like a marriage, I tell you, you fight all the time, but yet it's okay. (we argue about) just everyday stuff. "I don't have to wash the sheet! Yes, I have to wash it!" That's all.

Karen has two grown children in their late thirties. She has tried to get them to call their grandmother regularly, but they are both too busy. Karen likes being with her mother especially because she knows her mother is safe around her and she has learned how to work with her mother and her mother has learned how to work with her.

Caregiver Skills and Qualities

Karen was a nursing assistant of 23 years whose last client left the area so she was free to work for her mother when the program started. She also has her own health problems because she was recently diagnosed with diabetes.

Karen feels that she has the experience and skills to be a good caregiver for her mother,

I've done it for so long... I usually say, "Lord, help me to do good to others so that when somebody has to do to her, that they will do good." And sometimes I didn't feel like it balanced out but, I said okay, but I did my best and I did my part, and so I would recommend that someone can do it and do their very best. You just have to do your best, and when I was out there working eight or twelve hours I worked hard and sometimes I still don't get enough, because I care about the people. And, you know, they are people. They are older, but they are people and so you care for them because they are people. If my health allows me to, I'd

go back out there tomorrow into the work world, but I'm comfortable being just with her.

Karen points out that Florida, "...is an elderly town. Sometimes I wish they wouldn't be driving on the road, but I can't help it. They are independent. They are in accidents, but you have to respect them." Karen thinks that a caregiver needs special qualities to work with the elderly,

They should be understanding, they should be caring, they should be more giving because sometimes they'll just take every last strength out of you, but you find the strength to come back and deal with it. So it takes a compassionate person to really do the elderly.

The Consultant; Seeing if the Budget Can Go Further

Julia likes her consultant and Karen says that the consultant helps them and monitors their progress regularly,

She wants to know what is going on and how we are managing and we keep her up to date with everything. Also, if there was anything that came up that we weren't able to fund, then she would go see if the budget can go a little further. She is always inquiring of how it is working out and if there are any problems or anything that we can share with her. So we talk frequently on the phone and whenever it is visiting time, she comes here.

Problems with the Program

Although not specifically a problem with the program, Karen says that the staff at daycare assumes that her mother gets Medicaid and they are always suggesting that she increase the number of days she attends, which she cannot afford on her cash allowance.

Karen had some initial problems because she did not carefully keep track of her hours, but she is careful now and does not exceed the budgeted amount.

Karen and Julia have had problems with the manager of the independent living complex,

She kind of calmed down now, and I'm referring to the manager of this facility. I think she picks on my mother because my mom had an incontinency problem at one point and she said, "Well, you're not supposed to be here, you're supposed to be in a nursing home," and she was making arrangements so she could go move into a center, into a nursing home. So I said if you do that, I'll call HUD. I'll call somebody, I'll call anybody, so she backed off. (This) was a while back. And so, she's not as bad as she used to with her, but you know, she was not pretty nice to her in the beginning. She's (still) not okay, but she has me to deal with, so she'll think twice before she bothers her.

Benefits of the Program

Karen thinks that her mother's independence from agency help is a major benefit of the program. Karen also feels that the money she receives motivates and encourages her in her caregiving tasks, "It helps me. It brings me here every time, even more than the norm sometimes." She looks forward to receiving her money every two weeks. The cash allowance helps her buy incontinence products for Julia and pays for the one day in daycare that her mother likes so well. Karen also likes the control she has in the program do what needs to be done.

Consumer Story 16

Mr. Wallace Beal is a 71 year-old divorced African American man who lives in a low rise apartment complex in an economically depressed suburb. Mr. Beal is blind. He currently lives with his daughter Lisa, her husband and their two sons in his two bedroom apartment. The apartment was small and cluttered and smelled of alcohol. Lisa works as her father's caregiver. When the interviewers arrived Lisa was waiting outside to greet them and to share some of her concerns. There is great tension between Wallace and his daughter over the control of the money paid to her as caregiver. Mr. Beal was interviewed in his apartment with one of his teenage grandson's present watching television and falling asleep during the interview. Lisa requested that she be interviewed outside the apartment where she could not be heard by her father. Mr. Beal had an aggressive and hostile attitude throughout the interview and repeated that he was in charge of his household and wanted the interviewer to know that he considered himself to independent despite being blind. The interviewer was uncomfortable and worried about her safety during the interview in Mr. Beal's home.

Living Situation

Mr. Beal lives in an apartment complex for residents 55 and older. His daughter and her family live with him temporarily until their home is built. Lisa has 5 children, but only her two youngest sons are living with her. Her son's help their grandfather also, especially on the weekends. One of Lisa's daughter's was Mr. Beal's paid caregiver for a year and they also had conflicts over money. Lisa says that when she rates relationships on a 1 to 10 scale with 10 being the best relationship, she gives her relationship with her

father a 5, “He’s a great guy to talk to at times, when you need someone to talk to and at times he’s not. He has his good days and he has his bad days.”

Enrolling in the Program

Mr. Beal heard about the CDC program through a friend who worked for a service center for elders. Mr. Beal explains why he joined the program,

My main reason for joining the program is, it makes be not just independent, I’m independent long before I heard about it, it makes me more independent. And if you can be in a program like this instead of having someone to issue you something (it’s better). You know like they bring ‘meals on wheels’ in and they prepare it somewhere else and they transport it and when it gets to you you’ve got garbage. I’m telling you the natural truth, I’m plain spoken now. It’s garbage, but in this program here, I can get things and do things that I couldn’t do before. I’m in control of it. Instead of someone else being in control, I’m in control.

Previous Experience

Mr. Beal describes his previous experience as very unsatisfactory. He was especially unhappy with his meal and shopping situation,

Before the program came along I had food brought in to me for the week. Things were brought in once a week, one meal per day...They (Meals on Wheels) started bringing it in every day... and I wasn’t going to be home because I like to fish and like to go and I was out with my brother, he was a produce man and I’d ride with him, so I wouldn’t be home to get the food and a neighbor would have to get it or I would miss it. That’s what happened. It’s much better this way (because) I don’t have to worry about it.

Eventually, Meals on Wheels brought Mr. Beal a stack of meals for 7 days. He had to eat one meal a day with no second helpings. Getting and having enough food have been major sources of worry for him.

Mr. Beal also had agency workers several of whom he remembers with approval, but he did not like agency workers in general,

I wasn’t happy (with agency workers). This agency worker that came in... she supposed to be a professional. She’s going to mop the bathroom and the kitchen floor. She would go in and get the big pail, it comes out of the bathroom, she

carried it to my kitchen sink and put it to the sink and fill it up and then when she finished mopping she was going to take the water and throw it out along side the building where the grass is. Now what's this going to do? The chemicals are going to eat the grass up and you got a heck of a mess. Now these were supposed to be professionals well trained. If that's professional help, I don't need it. I don't want that, now that's a big difference from somebody who is taking care of things properly.

Lisa has experience working with the elderly in a nursing facility for about three years. She also worked in the kitchen of the facility.

I Can Do Many Things Myself

Mr. Beal makes it clear that he is independent,

I can use the vacuum cleaner to buff the floor. I can mop the kitchen, can clean counters. I can cook, I can sew, I can do many things myself. Then I can do my banking. I can do my writing. I can keep track of my bank account and different things. You give me something that's in print, I can read it. I have no problem with that. I read Braille so I can keep track of different things and I have a recorder... it's being repaired now and then I have what they call the Braille and Speak, I can use that to keep track of things.... I can do all that, I can do everything a sighted person can do, but I need a sighted guide because I'm blind.

Mr. Beal says that there are several things he does need help with,

Food is the most important thing. Without that you're lost, everybody has to have that. Cooking, feeding. The next one is going to the bank for me, helping me watch my monies and those are the two important things. Without money you can't get food, and without someone to prepare it properly you can't eat decent, and that's it.

Mr. Beal says that he needs help with his ADL, or "general living." Lisa cooks, does errands, shops, and washes his clothes. Lisa says that she gives him food three or four times a day. She puts the food in a bowl and tells him clockwise where his food is in the dish. Sometimes she cuts his meat for him. Lisa also takes him to the doctor. Lisa reads her father's medication bottles to him, he memorizes them and "brailles them out," or puts braille on the labels so he can identify them. She also gets Mr. Beal's clothes out when she takes him out, but he toilets, bathes, and dresses himself.

The Schedule and a Typical Day

Lisa works 5 hours a day, 7 days a week for \$10 an hour. Because she lives with her father she feels that she is on call “around the clock” and expected to work more than she is paid for. She starts work at 8 in the morning and sometimes has to leave the apartment to pay a bill or run an errand. She says that her father may not leave the house for two weeks at a time, “I ask him to exercise and he just sits.” Lisa says that her father is moody, “Some days he’s good, some days he’s not good at all. It’s very terrible. (He) knows how to dial the phone and call whoever he would like to call and then he sits on the phone and talks, a lot.”

When her father gets up in the morning, Lisa fixes him whatever he wants for breakfast,

I give him hot tea or coffee, grits, eggs, bacon or sausage, or whatever his heart desires, I feed him. Lunch, I fix him a sandwich or a big salad, and then for dinner I fix him a regular dinner.

Mr. Beal says that Lisa works an average of 5 hours a day, but I don’t really have to have a weekly schedule, like I say I got 24 hour service, you see.” He says that Lisa is worth every dime of the \$10 an hour she is paid, “and more, too.”

Lisa says that she and her father sit down and talk about what needs to be done, but they have a difficult time reaching an agreement.

He Tells Me What To Do: Money Problems

Mr. Beal says that he uses his cash allowance for caregiving services so he can “get a lot better services out of them.” Lisa is dissatisfied with the money arrangements and her relationship with her father. Mr. Beal insists that she must buy food for him from her paycheck. Lisa called the consultant who came to the apartment and talked to her

father about the money issue, but her father thinks the consultant is wrong and tells his daughter that the fiscal intermediary training tapes support his view of who controls the money. Lisa says that her father gets on the phone to tell other family members that she is trying to take his money because she refuses to give him money out of her paycheck, and she has problems with her mother and daughter over this issue. She is also unhappy because she had to pay back \$460 that was overpaid for caregiving hours to her daughter who was Mr. Beal's caregiver before Lisa. When her daughter was working for Mr. Beal he took \$300 out of her paycheck every two weeks, about half of her pay. Lisa complained to the consultant who told her that this was fraud, but to let it go because she thought Mr. Beal would soon be off the program. The consultant describes the problem,

... I went out to meet him because I didn't know him, and when I was out there I went over the CDC with him so we could understand what the project was about, and then the very next day, this caregiver called me and he had her giving him her check, saying that was his money, not her money, and of course, she didn't know anything about the project, so she did that. She got her paycheck, she cashed it and gave it to him, so I told her "no, that was wrong," she shouldn't be doing that, and that's when he stopped liking me. And my problem with Mr. Beal is that I can't prove it, but I just think that he uses the project for his own personal gain.

Mr. Beal's has a different opinion about the problem between himself and his daughter over the money,

Lisa and I we've had our difficulties because she don't really understand because the consultant who is a nice lady and intelligent, but she didn't tell Lisa this particular thing. She told Lisa that the monies that is given to me for this program is not to buy groceries. She didn't understand that I know from listening to the program (on tape), that I'm not supposed to take the monies myself and go grocery shopping or go out and buy different things, but once it comes to Lisa, it is Lisa's check. But now once you get it, how is she going to feed me if she don't take some of that money or some other monies and buy groceries?

Mr. Beal feels the consultant thinks he is a handicapped person who doesn't understand the program and she is not trying to understand his point of view. He says that the

consultant talked about dis-enrolling him from the program which he thinks is tantamount to consigning him to living in a nursing home where he has to do what other people want him to do and live in terrible conditions. He describes his Aunt who lived in a nursing home, was covered with bedsores, and had to lie in her own excrement. Mr. Beal feels that he understands the program and that he knows what his allowed, it is his daughter who doesn't understand what is required and the consultant who is patronizing him.

The Important Things for a Person to Have

Mr. Beal describes the qualities he thinks are necessary for a caregiver,

The important thing for a person to have with me, the first one is patience. The next thing that is important to me is for them to make connection, we connect with each other. The next one is, we must agree with each other. The next one is they must be like me, be humble when we are having conversations, and the next one is they must like what they are doing, and I must like it also and the sixth one is we must act on it, not just be a speaker about it, we must act on it. Those are the most six important things there is, but now you get someone to come in and you need to train that person (about) your likes and dislikes...

Lisa says that a caregiver has to be motivated and not easily pushed around if they want to work for her father. She thinks that her father wants to hire a family member so he can get the money.

It's A Good Job

Lisa may have difficulties working for her father, but she thinks that being a caregiver on the program is a good job and she would recommend it to others,

It's a good job and people who like older people always can help. If I'm going to the grocery store and I see an elderly in the store and they can't reach something, I volunteer and ask, can I do this for you and I think God will bless me more for helping that person. I think that I have done my good deed for the day.

Lisa would like to do this job for someone outside her family in the future.

Benefits of the Program

Mr. Beal likes the control he has on the program and the fact that no one tells him what to do. He describes the advantages,

Since I started this program there has been so many changes, I just feel good about it. Like I told you up front I can go when I feel like it, I can get up when I feel like it, I eat when I want to, many times as I want to. I got someone to take me where I want to go. I can just do things that I couldn't do before I got into this program... I'm sitting in the driver's seat. It's good being boss... The most important thing about me being in this program is that I can choose more or less to do what I want to do, not somebody else making decisions for me. That's the most important thing.

Consumer Story 17

Ms. Lynette Gabriel is a 35 year-old single African American woman who lives with her mother Barbara in a two story single family home in a middle class suburban neighborhood near Miami. The Gabriel's home is spacious and nicely furnished. Barbara is both Lynette's representative and caregiver. Barbara explains that Lynette is learning disabled and moderately retarded, and says that "her state of mind is like that of a 9 or 10 year old." Lynette attends a work center Mondays through Fridays. Barbara and Lynette sat at a kitchen table together for the interview. Lynette was friendly and seemed happy to be interviewed. Barbara answered most of the questions, but Lynette participated when she could and was especially interested in answering questions about her job.

Enrollment in the Program

Barbara heard about the CDC Program through Lynette's Medicaid waiver support coordinator. She was interested in the program for her daughter because she would be able to use the money to send her daughter to camp, which was not covered by the waiver.

Previous Experience

Barbara is a single mother who takes complete care of her daughter. She was frustrated with the Medicaid waiver program because money was allotted for home care, which Lynette does not need, but not for camp which Barbara thought was necessary for herself and her daughter. Barbara thinks that a family member who cares for someone is a better judge of what that person needs than the state. Barbara has had to get non-family caregiving for her daughter twice in the past; once when her daughter fell and had to stay

home for a week and another time when Barbara hurt her back and could not help Lynnette. The agency workers were needed to help Lynnette take a bath, help her out of the bathtub and help her dress. Barbara said that she also asked them to clean the bathtub. Barbara was not happy with the service she received from agency workers. The first worker was good, but the second worker, sent when she hurt her back, was always late, did a poor job of cleaning the tub, and did not help with Lynnette's clothes. Barbara explains the source of the problem with the agency worker,

What I found out (is) she had about 5 people that she was taking care of and she was only spending two hours with them. So she would come to me (late). She was supposed to be here at 6:00 o'clock, Lynnette's ride would come at 7:15 and you would see her not half doing everything (doing a rush job) so she could leave because she had somewhere she had to be at 8:00 o'clock. Well, it's impossible... After that I just told the Agency, don't bother sending anybody else up. If the bathroom is going to be half clean, since it was Lynnette's own bathroom, let her use it for 2 or 3 days and when I feel better, I'll clean it.

Medical Needs

Lynnette says that she does not take medicine, but her mother says that she takes something for behavior control and medication during her menstrual cycle because Lynnette's behavior becomes difficult then. Lynnette has had some serious medical problems including a month long stay in the hospital for gallbladder surgery. Lynnette's gallbladder attacks were worsened by the fact that she could not explain her problem.

She Needs Help with Certain Things

Barbara describes what she does to help Lynnette everyday,

She wakes up, she has to take a bath, she takes a shower. Well, I have to help her take a shower. She can get in the shower and she can bathe herself, but it's just certain things I have to go and help her with. To make sure that she washes all areas and she knows how to dress herself. And her clothes, she can go pick out her clothes, she matches up her colors. She matches her shoes and everything, it's just that I have to iron (her clothes). I wash for her, I cook for her, and she can fix her own food. She knows how to go to the refrigerator and pick out things. She

don't get the milk mixed up with the water or anything like that When we go grocery shopping, there are certain things that she is used to (like) her cereal (which she sees on television) And she can go right to that cereal. Once she sees you do certain things, she can go and do it. It's just the reading and writing (she can't do).

Barbara says that it is a help to her when Lynnette can find things in the grocery store.

She does all the cooking and cleaning and takes Lynnette to the doctor although Lynnette gets transportation for work. Barbara also takes her daughter out four nights a week to the mall or out to eat because Lynnette does not like to stay home.

The Daily Schedule

Lynnette is picked up for work between 7:25 to 7:45 and she returns home at by 3:30 or 4 p.m. Barbara takes care of Lynnette after that.

Use of the Cash Allowance

Barbara uses the cash allowance to pay for summer camp for Lynnette. She also uses the \$200 she receives for caregiving per month to take Lynnette out for meals and pay for cookouts and field trips sponsored by a club Lynnette belongs to. Barbara also used the cash allowance to repair Lynnette's broken glasses and took her to the dentist to get her teeth cleaned twice during the year. The cash allowance is very helpful to Barbara who is retired and on a fixed income.

Friendly and Outgoing

Lynnette says that she likes to be around a lot of people. Barbara explains that she is very friendly and outgoing and that as a mother she worries about how Lynnette will talk to everyone in the grocery store. Barbara says that she and her daughter have a very good relationship, "Lynnette and I, we always have a lot of fun together. We do things together, we go out in the evening together. It's just always fun things."

Caregiver Qualities

Barbara has a clear idea about what kind of skills and qualities a caregiver needs to do a good job,

Someone that's nice, trustworthy, kind, and patient. I feel that a person that's going to deal with handicapped people should love it, because otherwise if you're just going there for a pay check it's just not the thing that you should do. They need to be kind hearted and be a little bit aware of what a disabled person is all about, the different changes and stuff like that. You have to be able to deal with that.

Role of the Representative

Barbara says that as Lynnette's representative it is her job so see that her daughter is cared for, properly dressed and always up and on time. It is very important to Barbara to know that her daughter is well cared for.

Stress and the Need for Respite

Barbara says that she sometimes gets stressed over her daughter's care,

Sometimes getting up in the morning, when you first get up (is hard). 90% of the time Lynnette gets up, she's in a good mood, there is no disagreement, but like everybody, there are times that she can be difficult, and when she do, it's stressful for me because it's nobody but me to handle that. So it just all falls on me and it's a little stressful and sometimes it goes into three or four days, so it's not an easy thing to do then. One thing I do that really helps me with that is that she's my daughter and I love her. I know she has a problem, and I accepted this long years ago...Once you accept something and you know it, it's easy. It really is. You're going to have some hard days, but it's only going to last for so long.

Barbara knows that if she needs a break there is a group home she can have Lynnette stay at for the weekend. Her daughter's consultant recommended the place because it is not run like an institution,

In the kitchen they all cook together, they all sit down at the table together...everybody do everything together, so I can always call them there and they love her. She loves that! She's very comfortable down there for a weekend. That way, you know, if I really get too stressed I know I can always call and take her down there, but I haven't and she hasn't been down there for about two or

three years, but I know it's there. It relieves you sometime (to know there is a place). And after a couple of days everything is back to normal. But luckily I have never sent her there because I was so stressed out. Every time I ever sent her it's when she wants to go. She'll ask me, "Momma, when am I going back down to that place?"

They have a lot of different things. She loves babies, and they have her help feeding the babies and stuff like that, and she loves things like that, so I would say that usually after a year or so, she'll start asking me about going back down there. And it's usually like I pick her up from work on Friday evening and pick her up on Sunday, so it's like Friday evening, Saturday, and I go pick her up on Sunday, and she likes it because they go to church and she loves going to church because there's something to do every Sunday, so she's accustomed to that – she's used to that. And I feel good because one thing about Lynnette, if she likes something I know that it's alright. And I never send her anywhere unless I go and thoroughly check it out.

Barbara jokes that her daughter's consultant told her they could never find a place for Lynnette because Barbara is so picky. Barbara was very impressed with the group home, though, because it felt like a family home and was extremely clean and well cared for.

I Do It By Myself

Lynnette was happy to talk about her job at a work activity center where she puts napkins, spoons, forks, and knives and salt and pepper packets into plastic bags for restaurants. She is proud of the fact that "I do it by myself." Barbara has some concerns about the work activity center. She pays \$30.90 a day for Lynnette to attend and expects that Lynnette will work and participate in social activities. Barbara thinks that the center works the attendees too hard essentially making money twice, on the participation fee and on the restaurant contracts. Barbara visits the work activity center at least twice a month and has complained several times about the piecework approach she sees some of the supervisors taking. She witnessed supervisors urging attendees to keep working, even people Barbara thought were sleepy from medication and unable to concentrate. Barbara

says she sometimes is very upset after visiting the work activity center, “Some of these places make a lot of money off of people with disabilities.”

Problems

Barbara sometimes has problems finding transportation for Lynnette to activities so she has to take her. This can be inconvenient because she often does not have enough time to take a break or go out to dinner, but has go home briefly and then turn right around and pick her up.

Barbara also had a problem at the beginning with overspending on the cash plan which she has now rectified. Barbara says that the bookkeeping was a problem when the program was new, but has improved now that everyone knows what to do.

I Have More Control

Barbara describes the benefits of the CDC Program,

I have more control and more say so about what Lynnette needs than before, because (the state) had just this one standard plan for everybody and the things that Lynnette needs someone else might not need and a lot of things that someone else needs, she does not need it. I guess I just keep talking about that home care service, that was one of the things I think where most of the money was going, so most of Lynnette’s money was going in a budget for her home care which she never used, so it just really wasn’t benefiting me too much.

Barbara is also very happy that she can use the money to pay for Lynnette to go to camp. Lynnette looks forward to it and it gives Barbara respite which really helps to “reduce the wear and tear” she sometimes feels in the care of her daughter,

(the ability to pay for camp) kind of takes that worry off of me, whether I’m going to have two or three weeks to myself and it doesn’t matter whether I go anywhere. Some people take certain things for granted, but I don’t, when you can lay in your bed after 7:00 o’clock in the morning. You don’t have to get up at 5:30 or 6:00 o’clock or you can lay down at 5:00 o’clock in the evening before it gets dark and don’t have to worry about it...

Barbara says that she does not feel that she has a burden in her care of Lynnette, but “a responsibility,”

It’s a big responsibility to have to take care of just be available 24 hours a day, seven days a week without any outlet of your own. I think everybody needs some time, everybody needs a time out.

Consumer Story 18

Yolanda Benavides is an 11 year-old Hispanic girl who lives with her mother, father, sister, and grandmother in a middle class suburban house in the Miami area. Her mother Adela is her representative and her grandmother Carlota is her primary paid caregiver. One of Yolanda's 71 year old Aunts also works as a paid caregiver during the week after Yolanda gets home from school. The entire cash allowance is used to pay the two family caregivers. Yolanda has severe learning and behavioral disabilities. The family home was well-furnished and clean. The day of the interview was very hot and humid and the family was awaiting the arrival of a repairman to fix their central air conditioning. Adela and her mother Carlota were interviewed. Carlota was interviewed in Spanish. Yolanda was present during the interview, but is non- verbal.

Although Adela had dressed her daughter in an outfit that allowed Yolanda's arms to be tucked inside her shirt, she was still able to use her legs to attempt to kick the interviewer and the tape recorder. The interview was very difficult to conduct. The interviewer had to stand and move quickly around the room holding the tape recorder away from Yolanda's kicks. Yolanda was very hostile throughout the interview. It was clear though, that Adela was very skilled in handling the situation and was able to concentrate and answer questions while at the same time maintaining control of her daughter with love and patience.

Non-Verbal and Very Physical

Adela describes Yolanda's medical problems and diagnosis although it is clear that there is some confusion about what to call her daughter's problem,

The only thing that she has been diagnosed with as a baby (was) developmental delay. They didn't know how far her delay was, (but they knew) immediately

when they realized that she couldn't swallow (that) she is developmentally late. They don't tell you the word retarded, by the way. But, in the school setting, she is in a profoundly mentally handicapped class. In the hospital setting, they refer to it as mental retardation, too, and with the inability to swallow, they try to figure out if she would be classified under any particular type of syndrome. Initially when she was a toddler, they thought maybe she had William Syndrome, but later on, they discounted that. They ruled that out because William Syndrome, even though they do have certain facial features, they do speak and Yolanda is non-verbal and very physical.

During her first year Yolanda was hospitalized repeatedly for feeding through a nasal gastric tube until she received a G-tube at age 1. Adela says that the family tries to use American sign language to communicate with Yolanda, but that her daughter is very frustrated, probably because she cannot communicate, and very destructive. Yolanda's grandmother Carlota referred to the destructiveness, "This kind of thing no one can take it. She kicks you and since she's my granddaughter I take it." Carlota worried about her granddaughter's state of mind and says that she acts, "crazy. She kicks everyone."

Carlota worries about this because she has a back injury and is afraid that Yolanda will hurt her further. According to Carlota, Yolanda's kicking is a big problem,

She sleeps with me. I put pillows all over and then I sleep on the other side of the bed. I have to wait until she falls asleep, because otherwise she kicks me. I had breast surgery because I had water inside, and then she kicked me really hard. The doctor even told me to get a mammogram, but I had to wait for a long time before I could do it. Once she gave me a big bruise and she was wearing the rubber slippers. If she had been wearing the sneakers I don't want to think what would have happened to me. And sometimes she takes off her shoes, because she likes it, and she also kicks you when you try to put them back on. She kicks in a way I cannot understand. I don't know how she can do it. The furniture, we have to be careful with that. She hits everything. The computer, the furniture, the TV. You have to be walking behind her all the time.

Carlota has visible bruises on her arms. Yolanda also pulls her G-tube out. Carlota says that they sometimes call a neighbor who is a nurse or call 911 to have Yolanda taken to the hospital. Carlota cannot take her grocery shopping anymore because Yolanda has

tantrums, pushes the cart against things, lies on the floor and refuses to walk. Her grandmother is afraid that she will kick someone. Even though Yolanda is very strong, Carlota says that her daughter Adela is very patient with her, but she worries that Yolanda might hurt Adela.

Previous Experience and Enrollment in the CDC Program

With the Medicaid waiver, Adela could have a behavioral analyst and a caretaker come in to care for Yolanda several hours a day. Adela needed Yolanda “watched 100% of the time,” and Adela says that the caregiver really has to be someone who lives with them because the care is so constant. Adela was thrilled when she heard about the program because her mother was coming in every day to care for Yolanda without pay. Her mother Carlota did so much work that Adela comments,

I felt that I was treating her very unfairly. I felt that I was abusing my mother is what I felt. I said, “You know, you are doing all of the work and I can’t pay you.” So, then when they told me in this new program her grandmother can receive the money, I said that would be fantastic because that’s the person that does all of the work.

The Biggest Thing in the World

Yolanda needs help with many tasks from the moment she awakes. Adela describes some of the things that Carlota helps with,

She feeds her because Yolanda is learning how to eat by mouth.... We try to feed her about four times a day, and my mother will spend the time trying to get her to eat. That’s one of the biggest things that she does. She is the one that gets her ready for school, which is the biggest thing in the world because getting her up, getting her ready, getting her with the harness so that she can get on the school bus, I don’t see how someone from the outside can do that. She is the one who also puts her to bed. When Yolanda is tired, she goes to my mother. She knows that from the time that she was a baby she put her to bed. So we do it as a family unit.

She’s here for when the bus drops her off. Now last year, she was not riding the school bus because the school bus was very hot, and Yolanda was going through a

self-injurious situation, and every time that she would get placed on the bus, Yolanda would hit herself. So last year we had to discontinue the bus service. This year she is doing a lot better, and I am trying to get her back on the bus. So my mother helped in taking her to school. My mother also helps in being here for the days that she can't go to school if she is sick. She always has someone here.

Carlota also toilets Yolanda which is a stressful job,

Sometimes I get up (at night) and take her to the bathroom, sometimes she's all wet, or she wets the bed, and me too. She doesn't like to use the bathroom, and many times I have to clean her up myself. I have to have her standing up and I have to wipe off all the excrement with wet towels, then I sit her on the toilet a bit more, and then I clean her again and dry her, then put another diaper on her. Sometimes you can see her standing and you can tell she's doing it, and even if I run to take her to the bathroom it's impossible, because she cries, so I have to wait until she finishes, otherwise she doesn't finish and uses up more diapers. I always have to clean her up. It's been a few months now since she started getting her period, and it's very irregular. One day she just gets a little and then the next a little and then a lot, and it goes on almost for a month.

Carlota is very concerned about Yolanda's irregular menstrual cycles. In addition to toileting, washing, dressing, and feeding are also difficult,

Sometimes it's 4 am and she's already awake. Imagine, during work days, I have to get up early, because my daughter has to leave early. And then I have to feed her milk and all. Nobody appreciates this much. Sometimes Adela gets in the shower and Yolanda follows her, so then Adela showers her. Then I say, "Good, at least."

Carlota dresses Yolanda and makes sure that she wears gloves so she won't scratch herself. As already described by Adela, Carlota works with Yolanda to get her to eat,

As soon as she gets up I try to give her milk in order to have some hours before the next meal, with food, so that she can learn to eat. Many times I talk to her, I give her some banana and I put spinach or other vegetables, Gerber, or yogurt, something sweet, and since the sweet is in the tip then she eats it. Sometimes she's okay, but some other times you have to be very patient. I buy Gerber for her, prunes, apples, cherry, but she doesn't want any of that at times, she prefers bland foods, like spinach, vegetables with chicken, things that do not have a strong taste, and I try to give her banana, the actual banana. Sometimes I try to give her a bit of the other stuff, but then she doesn't want it. I try to give her prunes, because at times you see that her stomach is constipated... and after a little while you have to watch her because she will have a dirty diaper.

Carlota keeps a notebook where she records everything they give Yolanda to eat including the Pediasure. Carlota says that she buys some of the dietary supplements herself. Carlota worries about Yolanda's kicking and the scratching and remarks that, "That kind of thing is not the behavior of a retarded child." Adela says that Yolanda needs constant communication and behavioral therapy by the family. In fact, Adela says that one person alone cannot care for her daughter and she needs constant supervision so that she won't hurt anybody.

40 Hours a Week

Carlota does not know how many hours she is scheduled to work and told the interviewer to ask her daughter. Adela says Carlota is paid for 40 hours a week of work at \$6.75 an hour although she works much more than that. An aunt of Yolanda's works 20 hours a week for \$6.75 an hour. She works in the afternoon when Yolanda returns from school so that Carlota can eat or leave the house for appointments or errands.

Adela says that Carlota's schedule is the same as Yolanda's,

My mother's weekly schedule is because Yolanda wakes up very early in the morning. That's another thing, so my mother is on the same schedule as she is. Yolanda gets up anywhere between 5:00 and 6:00 in the morning and starts roaming the house.

Adela gets ready for work and cannot care for Yolanda in the morning so Carlota does everything. Adela realizes what a difficult job her mother has and it is clear to her that only a family member would be willing to do this amount of work with Yolanda, "How could you get anybody (else) to do all this? It's a 24 hour job, so you would have to have a 24-hour person is the only thing I can figure..."

Experience and Qualities of the Caregiver

Carlota has a doctorate in pedagogy, studied psychology, and worked with children for many years. For Carlota a caregiver needs, “patience, a lot of patience, love children. That’s why I studied to be a teacher, and that also helped me deal with her. If it wasn’t for that I would go crazy, and with all that sometimes one (still) goes crazy.”

Carlota could go on trips with her other adult children, but she does not want to leave her daughter Adela to deal with Yolanda on her own.

Carlota says that Yolanda seems to have more respect for her Aunt than she does for her grandmother, maybe because Carlota provides most of the care, “...even if she kicks me one loves her and feels bad. I would like to hold her and kiss her, but she’s kind of tough, except for with her father because he gets home and takes her out...”

Problems with the CDC Program

Adela has had some problems with the accounting and payments to caregivers because the budget statements are difficult to read and she was not able to keep track of the balance.

Benefits of the Program

Adela likes the state consultant who she says is very supportive and helpful. She thinks that the best part of the program is the ability to pay the family caregivers,

The people who are getting compensated are the people that need to be compensated because they are the ones that are working as a team together as Yolanda has needs. They can always be here. It’s not a scheduled time. It’s not someone that is coming from a certain time to a certain time every day. Whenever I need my mother, she is available. And it is someone that knows Yolanda very well, knows everything about her, because she has raised her since she was born.

Adela says that the most important benefit of the program is, “The freedom to spend the money on what you feel is important for your daughter.”

Consumer Story 19

Jay Andrews is a 7 year-old African American boy who lives with his parents and his 4 year-old sister in a house in Miami. He wore jeans and a T-shirt and looked clean and well groomed. Jay has two non-family caregivers. The interview was conducted with Jay's mother Sandra at the home of his primary non-family caregiver Leslie. Jay and his sister watched television and played with toys during the interview, occasionally becoming very noisy. Sandra was injured in a car accident before the program started and was not able to work with her son in the way she had before. Jay has been diagnosed as autistic and has behavior problems and delayed speech. Sandra says that her son flaps his hands and spins. He has to be watched carefully because he will put things into his mouth. Sandra first heard about the CDC Program through a brochure in the mail.

Previous Experience

Sandra said that her son had trouble with agency workers because they had so many different workers that he could not adjust to them, "...the people were very nice, but some of them just didn't click with Jay." It is also very important for Jay to have structure or he "backtracks," or become less functional. Sandra found that her son did not have structure or consistent discipline with the various agency careworkers. Sandra got to know Leslie through Leslie's daughter who occasionally babysat Jay after school. When she heard that Leslie had early childhood education experience, she asked her if she would like to work with Jay.

He Needs Help With Different Things

Jay receives care from several people. He has 2 non-family caregivers who provide personal care and therapy. One of the caregivers will be quitting soon so Sandra

will have to hire someone else. Sandra says that they also have a behavior therapist who works with Jay about 10 hours a week, but has stopped for several months until he develops a verbal plan for Jay. Sandra thinks that behavior therapy is very important, but she wishes her son could get speech therapy. Sandra and her family also work with Jay themselves. A neighbor friend of Sandra's will sometimes come to their house and take care of Jay so Sandra and her husband can get a break.

Sandra describes the kind of help Jay needs,

Bathing, assistance with putting on his clothes, his shoes, just helping him with different things, toileting. He doesn't wear diapers now, he doesn't wear Pampers. Actually, he's potty trained, you just have to watch him when he goes to the bathroom. (He tries) to play, when he flushes the toilet it excites him...He can feed himself, if we don't supervise him then he'll try to do different things. Before he wasn't even able to feed himself, but now he's doing it.

Sandra is very happy with Leslie. Leslie provides personal care, respite care and what she calls "the resat," or behavior therapy,

Leslie assists him with putting his clothes on, taking his clothes off, she bathes him, when he comes home, she teaches him to bathe, watches his manners at the table, teaches him those types of things, she takes him to the park for me, she helps him to interact, and other things. It's a lot.

Leslie describes how she works with Jay,

He's able to go to the bathroom on his own. I just have to make sure that he wipes properly. We've been working on turning the water on and making sure he's using the cold water and the soap and making sure he's washing his hands properly...I assist with bathing, and we're working on getting him to bathe himself and dry himself, re-dress himself, comb his hair and brush his teeth to get him to be as independent as possible. He's able to feed himself. You can put whatever (is) for dinner in front of him and he uses his utensils, he uses his napkin when he gets done...I'm the paper plate queen!

He knows when he gets done with his meal to take his plate off of the table and put it in the garbage and his cup or whatever, so he's really good about that and we've been working on him putting his plate and napkin and cup and fork there, that type of thing.

Just to be as independent as possible and then we'll do peanut butter and jelly sandwiches, I'll make sure to let him use the plastic knife so he can spread it as much as he can, cheese whiz, that kind of stuff. Something that he can do and feed himself.

Leslie says that Jay "looks normal in every way," but as he gets older his behavior problems become less understandable to people outside the family. She describes taking Jay to church when a woman sitting in front of them complained that he was disruptive. Leslie explained that he was a "special needs" child and autistic, but thought that the woman did not understand what that meant, "...if I had said retarded or something she may have been able to understand."

The Caregiver Schedule and Pay

Leslie works about 10 to 15 hours every week mostly on Wednesday and Saturday. She may also work on Tuesday and Thursday if Sandra needs her help then. The second non-family caregiver works about 10 hours a week often on the weekends or other days in the week. Leslie takes care of Jay from 5:30 p.m. until 9:30 p.m. approximately twice a week. Leslie feeds Jay, does activities with him, and helps with personal care. Jay is in school during the day and then in an after school program until 5:30. Leslie says that Jay is very comfortable at her house. Her husband sometimes takes him to a local park after work or into the back yard to play with the dog. Leslie comes home from work when Jay arrives. She can take Jay for an evening if Sandra calls her by 11 in the morning to let her know, "If I'm available then it works out."

Sandra pays the caregivers between \$8 and \$10 an hour depending on the care they provide. Behavior therapy is \$10 an hour while personal care is \$8 an hour. Sandra often augments the program pay out of her own pocket to cover extra hours of care. Sandra says that she supervises the caregivers by checking and seeing how they are

doing. Leslie says that she and Sandra sit down together discuss what skills Jay needs, and make a list of what to work on. Leslie then uses the list as a guide for her work with Jay.

Use of the Cash Allowance

Sandra uses the cash allowance for the caregivers. She tried to get permission to pay for a computer for speech therapy for Jay, but was turned down by the program. Leslie is grateful for the pay because she has college tuition payments to make for her daughters.

Somebody Who Will Be There For Jay

Sandra thinks that a good caregiver is dependable, “will be there” for her son and has the skills to work with him. She likes Leslie because she is a teacher and has her own family so she has experience with children. Leslie has an A.A. degree in early childhood education and works as a Director at an early childhood education center. She also mentions that she is certified in CPR and First Aid. Leslie thinks that a caregiver needs, “a lot of patience... and a general understanding of developmentally appropriate practice.” Leslie thinks that a good caregiver should not expect too much or too little of a special needs child.

Leslie describes her relationship with Jay as “very good.” Sometimes Leslie will pick him up from his after school program if Sandra is running late and she says that Jay is always happy to see her, “He responds well with me, actually he responds better when his mother is not around, like now he’s a little hyped there...”(referring to Jay playing noisily with his sister). Leslie describes her relationship with Jay and his family as

“professional,” but she worries about what will happen to Jay when he gets older because, “...there’s not a lot of assistance out there...” as children with autism grow up. Leslie likes the fact that she can see the results of her labor with Jay. He is developing more self control and she can take him to more public places than when she first started working with him. She takes him to church and to youth groups and, “... to a certain degree, he’s able to fit in with the other kids as long as the group stays small and it’s not too loud.” Leslie also likes it when Jay masters a skill. The most difficult part of working with Jay is when he is not interested in working on a skill or he loses a particular skill he had mastered. Leslie wishes that she could communicate with Jay more easily, but he cannot express what he needs or wants, “... It would be a great thing if he could say, ‘I’m tired, I’m sleepy, I’ve had enough of that skill,’ or ‘ I don’t want to do this anymore.’... I do a lot of guessing (because he can’t communicate).”

Leslie and her husband enjoy working with Jay. Leslie’s husband enjoys the bond he shares with Jay, but her worries about how he will care for himself when he gets older.

Leslie describes the personal relationship she and Jay share,

One of the characteristics of autism is that they like to feel part of your body. (For example) touch your ear, and I have the hardest time with my husband saying, ‘don’t let him pull on your ear!’ (but) This is what Jay’s got! He’s got so few joys in life! Let him pull on my ear! My husband and I have really developed a bond with him. Jay responds very well, very well. And that’s a good thing. His mom says, ‘I wish he was like that with some of the other people that have him,’ I think that even though he’s not able to verbalize, he senses that he is loved and we do care about him. I just enjoy seeing him develop. I enjoy seeing him growing and learning his tasks.

Leslie feels that if Jay can grow, mature, and become more independent he may be able to live in a group home in the future.

Benefits of the CDC Program

Sandra is very happy with her son's participation in the program. She works well with the consultant who acts as a guide. She has also found the accounting people helpful when she needed help with the financial aspect of the program. Sandra likes the help her son receives in the program and she sees an improvement in Jay, "He's come a long way, (before) he couldn't say bathroom, he would have to take your hand and show you, but now he can say bathroom. As far as eating and sitting like a big boy, he does that better now, if he makes a mess he tries to get a mop or broom and tries to clean it up." Sandra likes the program because,

I get to run the program the way I want to.... I thank God for the program, put it that way. It has helped a whole lot. There's not a lot of programs out there for autistic children and I really appreciate this program.

Consumer Story 20

Bonnie Aguilar is a five year-old Hispanic girl with cerebral palsy and seizure disorder who lives with her parents, her twin brother, and an older brother in a home in suburban Miami. Her mother Cara is her representative. Her elder brother Jason is 7 years old and is autistic. He is also enrolled in the CDC Program. Bonnie's non-family caregiver, Alma, takes care of Bonnie and Jason. Alma is in her early sixties and is originally from Central America. She was interviewed in Spanish. The children call Alma, Tia, or "Aunt" even though she is not related to them. The interview was conducted in the Aguilar's home with Bonnie's mother, non-family careworker, and all three children present. The home was clean, bright, and child-friendly.

No Consistency

Cara found out about the CDC Program through a special school that Bonnie attends. Cara was very interested in participating when she heard that she could choose who came to work for her.

Cara says that she can tell "horror stories" about her experiences with agencies when she felt that she and her children were at the mercy of whoever the agency chose to send to her home,

I didn't choose who came into my home. A woman would come into my home. I would hear her yelling at my children. They (the agency workers) would come when they wanted. I am waiting for a care giver to come, and I would call the agency.... They didn't care whether they showed up or not. I saw some of these care givers yell at my children, and I have one (an autistic child) that didn't speak at all which bothered me. I would never leave my home because I he couldn't tell me what was happening to him.

Bonnie does have a mouth on her, but she is five years old. At the age of three, she wasn't able to tell me a lot of what (was happening), so I never felt safety with my kids. You would have (an agency worker) that was really good, and maybe she would be here for a month or two, and then all of a sudden they would

never show up again. My kids had no consistency.... in the beginning (with a new caregiver) everything is tough when you start a new job until you show them. So I would waste my time showing them how to put on the (leg) braces, what we do, what our routine is, especially in my home. I like to have a home with a routine and stability for my children. You get them all trained, get them all ready, and then they never show up again, and here comes a new person.

Cara had a caregiver she liked who she hired in the CDC program, but the woman began bringing her own son to work and began “to slack off,” so Cara had to find a new worker.

She Needs Help with Pretty Much Everything

According to Cara, while Bonnie’s speech and vocabulary are well-developed, she has difficulties with hand/eye coordination and needs help with, “getting dressed, feeding, eating, bathing, all of her health care.” Bonnie is mobile and she can do some things, “She can eat finger food on her own, but anything like soup or spaghetti (we have to help).” Cara describes what Alma does for Bonnie,

She bathes Bonnie for me in the mornings. When she gets here from 9:00 until 5:00 (during the summer), she will work and help me bathe her, dress her, feed her, and then we take all of the kids and we go to the park. We take the kids to the pool. Alma helps me with the other (2 children) when we are at physical therapy or while we are at occupational therapy. She helps me with the laundry. She helps me with Bonnie’s room, her linens, and things like that.

Alma adds to Cara’s list of tasks. Alma gives Bonnie her medicine, gives all the children movies to watch and supervises the children because Bonnie is “mischievous” and has to be watched carefully to keep her from getting into trouble or falling down.

There Is Another Child Involved

Cara says that Alma works approximately 50 hours a week at \$12 an hour and helps with both her children who are in the program. Alma works more in the summer when the children are home from school. Cara also hires several college girls for respite

care on the weekends to take the children out to MacDonald's or so she and her husband can go out for a meal. The respite workers are paid \$10 an hour. If neither of the young women can help, Alma will sometimes provide respite care for Cara at the respite salary. Cara defends how much she pays Alma and the fact that she needs respite care by pointing out that "there is another child involved," she has two children with developmental disabilities to care for. Cara uses the children's cash allowances on alternate weeks to pay for Alma's salary and respite care. Cara says that she has to be very creative to find and pay for care with 2 children on the program. When the children return to school Alma will work from 2 p.m. to 7 or 8 p.m. every day during the week. Cara supervises her children's care, "I do not work. I am home, and I have three kids with special needs.... I am here overseeing everything (and) participating in it." Alma agrees that Cara supervises her work, but says that they talk together about the children. Cara gives Alma advice on how to handle the children's anger or bad moods by playing with them and helping them to get out of their bad moods. For Alma, this is to be expected, "...But that's like all children. As we say in my country, "they get angry just because."

She Used To Work For A Cousin

Cara met Alma through a cousin who had hired her previously and Alma has worked for them for about a month and a half at the time of the interview. Cara likes hiring non-family workers because she thinks it is easier to tell them what to do. Cara and the children call Alma "Aunt" and she has an affectionate relationship with the children, speaking to them in Spanish and using pet names when she talks to them. Alma thinks that she has a very good relationship with the whole family and that they treat her

well and depend on her, “I don’t just leave her with unfinished tasks.” Alma says that she likes children and thinks that Bonnie is very nice. Alma realizes that Cara needs help caring for all three children,

Like I told Cara, I am here until she tells me that it’s no longer needed, it cannot be done, or we are not in the program any more. She really needs help with the children, it’s three of them. They are all very nice. The children and the parents are very sweet. She tells me some times, when I talk to her about going (back home), she says “Oh, no Tia, you cannot leave me.” The entire family tells me that I cannot go. She really needs help.

Somebody Who Loves the Children

Cara thinks that a good caregiver will love the children. It is also important that they know CPR, “They don’t need to be a rocket scientist. They need to know your basic CPR and know that they have to dial 911 and what to do. After that, everything is love.”

Alma thinks that it is important to be calm, patient, and know how to take care of children. Alma has had extensive experience raising children and clearly enjoys their company. Cara feels that her most important job as representative is to find the right person to care for her children.

Problem with the CDC Program

The only problem that Cara has experienced is when she sent a timesheet late so the careworker did not receive her check. Cara paid the caregiver’s salary out of her own pocket until the check came.

Benefits of the CDC Program

Cara likes the fact that she makes her own decisions for her children, “There is no agency out there telling me what my children need because no one knows what my children need more than I do as a mother.” Choice is the “bottom line” for Cara. Cara values being able to leave her children in her own home with a caregiver like Alma, “ I

know that my children will get a lot of love from this woman and they are safe. Safety and love, you can't ask for more than that.”

Consumer Story 21

Ian Scofield is a 33 year-old white single man with Down's Syndrome. He lives with his mother Marilyn and his non-family caregiver Frances in a suburban home near Miami. The interview was conducted at Ian's home after he had just returned from a day training program. Ian was nicely dressed and very polite. As soon as he got home his mother asked him if he wanted a snack, which he got himself from the refrigerator. Ian was present during the interview, but was very intent on eating his snack and did not participate in the interview. Marilyn Scofield is a retired elementary school teacher who has always cared for Ian herself. Frances works full time as an Office Manager. She and Frances have been housemates for almost 25 years. Frances has a son about Ian's age and a daughter about four years younger. The children grew up together and Marilyn says they are like siblings. Marilyn and Frances met when Marilyn taught at a grade school and Frances was active in the PTA there. They both went through divorces at around the same time and decided to become housemates and raise their children together. According to Marilyn, since they have been housemates for so long, Frances has known and helped Ian for a long time. Frances says of Ian, "I think he appreciates my help and we're friends." Frances says that Ian does not know that an hour a day she is paid for her caregiving.

Deciding to Enroll

Marilyn heard about the CDC program from Ian's coordinator who gave her a brochure to read. Marilyn had never used an agency and did not realize that Ian was eligible for personal care assistance. She decided to enroll in the program,

Because I wanted Ian to have more options in who gave him personal assistance and respite rather than having to go through agencies and try to find strangers.

The turnover in agencies, I understand, is quite high, so even if you get someone that you develop a rapport with, they can leave, and then you start over again. I wanted the freedom to use someone he knows and has known for quite some time.

The personal care assistance is very helpful to Marilyn because, “I don’t have to be constantly helping him and I can get some respite. I didn’t have that before I became a part of this program.”

Previous Experience

Although Marilyn never used an agency for Ian’s personal care, she did rely on state funded transportation for Ian to and from a Goodwill program. About 6 years ago, Ian had a terrible experience on one of the buses,

The only thing that I had to depend on once when he was at Goodwill in the Goodwill Program was the public transportation, which was disastrous because they got lost one afternoon, and he was gone, left Goodwill at about 3:30 in the afternoon and at 8:30 at night I was still trying to find him.. It was a very bad experience. They had a driver that couldn’t read maps, didn’t speak English, didn’t have his communication system on or couldn’t understand the directions that he was being given by the dispatcher. On top of that we had a terrible, terrible storm that day. It was thundering and lightening and pouring down rain. And when they finally located the driver Frances said tell him to stay right where he is. You tell me where he is, and I will go get Ian off that van. He was scared to death when he got home, too.

Marilyn says, laughing, that she chewed her nails to the quick that day. Since Ian is on the CDC program, “I can provide the transportation with a transportation company providing part of the (return) transportation, I don’t have to depend on what the county claims to be equivalent for disabled people, which is not equivalent for disabled people.”

Needing Assistance

Marilyn describes what Ian needs,

He needs help with some food preparation, with his meals. He needs help with his laundry. He needs some assistance with showers because he tends to use the water way too high (in temperature), and I am afraid that he will get burned, so he

needs assistance with that. Medication, he needs some assistance with the medication.

Marilyn describes what Frances does to help Ian,

She assists him in the morning with his breakfast, and he does need some assistance with shaving, so she takes care of that. She gives him his morning medication, and he pretty much picks his own clothes, but if something is not appropriate, she guides him into something else. Then in the evening at dinnertime she assists again a little bit with the meals and with his shower and the water temperature and that type of thing.

Marilyn and Frances work together to prepare the meals, “If we are going to feed Ian earlier because sometimes we eat later due to our schedules, and then she will do his dinner while I am doing his lunch for the next day.”

A Typical Day

Marilyn describes a typical day for her son,

He gets his guidance in getting dressed. He has his breakfast, and then I take him to the day training program, and then he is there until about 3:15 or 3:20, and then he comes home and he has his snack, and then he usually watches television until I get home, which can be 3:30 or quarter to four. Then two days a week, this being one of them usually, we go to the gym. I take him to the gym so that he can work out, and I try to get him one afternoon a week to the pool to swim. The season will be starting in a couple of weeks for bowling, and then he will be bowling every Tuesday afternoon. Then when we get home from the gym or whatever, he watches a little bit more TV, and then he will do his shower and have his dinner. Then he laxes out until he goes to bed. That’s kind of a typical day.

Frances works for 30 minutes in the morning and again in the early evening Monday through Friday. On Saturday and she works for an hour. Frances is paid \$7 an hour for nine hours a week of work. Marilyn thinks that the most important thing that Frances does for Ian are helping with his meals and medication and monitoring his safety when he showers.

Frances thinks that one of her most important tasks is keeping Ian on track,

I help him in the morning and he gets up at the proper time, he has a tendency if the alarm goes off to turn it off and lay back down.... He needs a lot of prompts, otherwise he loses his time. So I prompt him a lot in the mornings because we are on a schedule. He has to leave at a certain time to go to work.

(I follow) the same procedure (in the evening)... again the night is with the shower, making sure the water is adjusted right. I do help him at different times on the computer. He likes to work on the computer so when we do have a few minutes or something, we'll sit down and he will work some basic programs on the computer, there are a lot of little things that I do...

Ian often lets himself into the house with a key after work and is alone until Marilyn gets home. Frances worries about him if he is alone for more than an hour at home so she will call him from work several times to check on him.

We Work Together

Marilyn and Frances have known each other for so long that Marilyn says they work together on what Ian needs. They have a routine, "She knows what she's going to do and I know what I'm going to do, and it just works out." Frances feels that she has known Ian so long that she knows him as well as Marilyn does. If Frances has trouble getting Ian to listen to her she may ask Marilyn's advice. Frances has 2 children of her own and feels that her "motherly instinct" helps her work with Ian.

Marilyn thinks that a good caregiver should be like Frances. Frances really knows Ian, "Somebody who is patient and kind and allows him to make certain decisions for himself that he is able to make and yet knows when a decision he might make is not the appropriate one and guides him that way." Frances thinks that you have to really care about someone and their well-being to be a good caregiver and you must be patient. Frances takes care of Ian because it gives her a sense of fulfillment, "...getting paid for it is not why I do it." She is also able to help Ian because he is mobile. Frances says she could not physically be Ian's caregiver if he was in a wheelchair and she had to lift him.

Frances has a good relationship with Ian, “I’m glad I’m able to help him and I think that I have taught him some skills, and I’m glad about that, and he is a very nice person, a good individual and he’s pleasant to be around...”

Use of the Cash Allowance

Marilyn pays for Ian’s transportation to the day training program. She drives Ian in the morning and the van brings him home at night. Marilyn takes Ian in the morning so he doesn’t have to get up at 5:30 a.m. to take the van and this also saves her money because the van is so expensive. The rest of the cash allowance is used for the caregiver’s salary. Frances likes to use some of her salary to pay for special things for Ian like a trip or computer programs, “I’ve been able to give Ian some extra things that he hasn’t had a chance to have before.”

Benefits of the Program

Marilyn describes the benefits of the program for herself, “It gives me a little more freedom because I can get someone to watch him that I know and I can rely on and I am not afraid to leave him, so it gives me some relief.” Marilyn did not have any respite until Ian became a part of this program. About 3 years previously, Marilyn had a medical emergency and was in the ICU and then the hospital for seven days. Frances and Frances’ parents took care of Ian then. Marilyn thinks that if she has a problem that Ian will have someone who knows him to help and he doesn’t have to go to a strange place or get help from someone he doesn’t know.

Consumer Story 22

Jenny Hollins is an 11 year-old African American girl who lives with her mother and father in a poor urban neighborhood in the Miami area. Jenny has severe developmental and behavioral disabilities which her mother describes as fetal disorder developmental delays. Jenny needs intense supervision and patient care. Jenny's mother Anita acts as her representative and provides unpaid care. Jenny's Aunt Cathy, who lives in a house nearby with Jenny's Grandmother, is Jenny's paid family caregiver. Jenny's Grandmother also helps care for Jenny. Cathy helps Jenny before and after school during the week. The interview was conducted at Cathy and her mother's home with Anita while Jenny was noisily busying herself with a plastic toy. The interview was very difficult to conduct with the Jenny present because of her repetitive and compulsive actions. She shook a plastic toy with a ball inside for the entire hour. Anita was not at all bothered by her daughter's actions and was very loving throughout the interview, at times trying to calm and comfort Jenny. Jenny wore a school uniform, a helmet, and a large bib. Anita explained that Jenny had to wear her helmet at all times to avoid injury. Cathy is currently trying to teach Jenny to feed herself and to use the toilet by herself.

Previous Experience

Anita describes the limited services her daughter received through the Medicare waiver,

(Jenny received services from) Developmental Services through the Children and Families, that's what it was through. Basically, I would go into the case worker and any request that was needed they would say "Yes, this is allowed, this is not allowed." Respite care was really limited....

At first Anita worked with a social worker, but then she had to receive services for her daughter through an agency. A person from the agency acted as Jenny's

representative and Anita had to let the agency representative know what she thought Jenny needed. Anita describes the process,

(The agency) evaluated Jenny and they did it that way to determine what her needs were. But I can see what she needs. I know when she's going through more diapers. But then, you had to go through (the agency) and they had to come out (to see what she needed) and it was more time consuming.

As Jenny's representative Anita has to, "keep up with the budget, make sure that everything is in line, send in the time sheets," and keep track of receipts.

Enrollment

Anita heard about the CDC program from her daughter's caseworker and decided to try it because she was told that she would have more control over the benefits her daughter receives.

Needs, Tasks, and the Daily Schedule

Anita says that Jenny needs help with everything. When the interviewer probes for a list of needs, it becomes clear that Jenny needs help with all activities of daily living. The family is trying to potty train Jenny, but they have not yet been successful. Jenny's Aunt Cathy tries to help feed Jenny and provides basic personal care. According to Anita, helping to feed Jenny is very difficult, "She's at a point where she slings food..." Cathy describes what she does for Jenny as, "Feed her, diapers, walk with her, bathe her, brush her teeth, like a one year old."

Cathy works 8 to 10 hours a week for \$10 an hour. Anita says that she supervises Cathy, but Cathy says that no one supervises her work. Cathy's schedule with Jenny varies with the school year and is more flexible during the summer. Cathy says that she is not paid for all the care she provides. Cathy helps Jenny before school for 30 to 45

minutes and after school from 4 to 6. Anita drops Jenny off at Cathy's house after school. Anita describes Cathy's schedule with Jenny after school,

She puts her on the pot and lets her sit there to see if maybe she'll do anything for maybe fifteen minutes or so and then she prepares her food, feeds her, tries to have her dress and feed herself once in a while. (She tries to teach) basic self-care skills, trying to get her use to brushing her teeth and stuff, washing her face. That never worked!

Use of the Cash Allowance

Anita bought a helmet for Jenny when she began hitting herself. She describes how other expenses increase, "Just recently I had to increase the diaper order to every three weeks because I was running out before the other ones would come in." Anita says that the extra money for diapers is a great help for them. Anita will also use part of the cash allowance to help pay for a summer camp program for Jenny which is important because Anita has to work and needs care for Jenny during the summer, too.

Caregiver Experience and Important Qualities

Cathy has been a Certified Nursing Assistant for 15 years and has worked in an Alzheimer's Unit in a Nursing Home. She thinks that a caregiver must be, "in good physical shape and be able to get up when they are needed" in order to do a good job. She prefers helping people for money and is glad she is paid for Jenny's care. Anita says that the most important quality for a caregiver is, "patience... dependability, to make sure they're there when you need them."

Benefits of the Program

Anita says that she has more freedom with the CDC program, "If I need more diapers I call up and I get the orders. I don't have to wait and put in a request for them." She likes not having to go through a middleman to get what she needs for her daughter.

The caregiving is a help because Anita hopes that it will help Jenny become more independent.

Consumer Story 23

Nikki Cannon is a 53 year-old single African American woman who lives with her mother in a house in Miami. Ms. Cannon has been a quadriplegic for 32 years as the result of a car accident. Her mother Sharon is her caregiver. The interview was conducted in Sharon's home. The home was decorated with family pictures and a wall hanging of the Last Supper as a centerpiece in the living room. The house was clean, although the walls and furniture were old and worn. Ms. Cannon was lying on an old hospital bed covered only with some bed sheets. Her upper arms and shoulders were uncovered. She could only move one arm and her head had limited movement. In addition to a television set, the room had two bureaus for supplies such as rubbing alcohol, skin cream, room scent, powder, and cotton balls. Ms. Cannon's ten-year old granddaughter came to visit toward the end of the interview.

I'm What They Call a Quad

Nikki describes her medical conditions,

I'm what they call a quad for quadriplegic. I have been for 32 years from a C6 injury and I suffer from diabetes besides the paralysis, and I had kidney surgery. I have one kidney left. I also have a couple different arthritis areas.

Sharon says that it is difficult to get her daughter out of bed because she has been paralyzed for so long,

She stays in the bed unless the kids come by. The kids are all grown and have husbands and children and all. They come by and get her up and get her out, but she is such a heavy person. And now after laying up, her joints are stiff (so) the knees and legs don't know how to fold. You can hardly get her in a chair. They do get out, but she don't like to get up so if you get her out, you're good, because you have got to keep on after her. She likes to go (out) sometimes and sometimes she don't. Most of the time she feels pretty good. If she gets sick, we call the paramedics and they get her over to the hospital. The hospital is close and she has been going there for years, so we call the doctor, and he will call there so that they are expecting us... She gets sick sometimes, but not too often.

Ms. Cannon and her mother have dealt with this so long that they are used to the routine and know the pharmacists at the local drugstore. Sharon says that her daughter “is in good mind” so she remembers all her medications and if the pharmacists have a problem they know to get in touch with Ms. Cannon’s doctor. Sharon is thankful that the doctor and the people at the drugstore are “so good at understanding” because it makes her life easier.

We Put Our Resources Together

Nikki remembers her car accident and the way it affected her family,

My mamma sold her home and my dad worked hard because we were raising about 9 to 12 kids that were all in our family. I had one daughter, but my mamma also raised my daughter, my brother’s daughter, and she had my sister, two of her sisters, two of her brothers. My aunt had died in an accident with me. She had her son and two daughters. So all of these were my mother’s and my father’s responsibilities.

My father died in 1989, so then my mamma had to find work again. She was a beautician, so she started driving a bus again, and I had social security and the two of us, we had to budget it and run this family... We had to put our resources together and learn to do this. I knew that we could do it, but we worked on a small budget.

Nikki says that she always relied on family for help. Sharon describes the importance of family in her daughter’s life,

Nikki is happy because she has a phone and a television and her daughter is married so she got two grandkids and I got three grandkids, so this week the oldest little girl who’s 10, they don’t go back to school until next week, so she has been spending the day mostly here. Nikki loves them to death. So, they are here in and out, back and forth on the phone, so it’s not too lonesome. I go to church, my church is down the street there, a hop, skip, and a jump.

The Program Sounded Interesting

Nikki heard about the program through workers in another program. Nikki and her mother have tried many different sources of assistance, but were dissatisfied with the help they received through agencies. According to Nikki,

...None of those people appear to be very skilled with what they were doing or they were limited to how much they could help. They couldn't do anything internal or real medical, and my mom basically has done it all, all through the years, so when this program came up, it sounded interesting... It seemed to be perfect. It would subsidize some of the care and then she could save some more money and help me supply the things I need, the medical things. So we gave it a shot.

Nikki explains that she and her mother “function like a hospital.” When agency workers were late, her mother had to go ahead and do the work and then agency workers had to find something to occupy their time when they finally showed up. When Nikki needed help with changing the bed or eating or taking medications the agency workers would be on their lunch hour. Nikki noticed that agency workers did not want to do what she calls “scrub work.” She often caught agency workers “doing the hand thing” and had to ask them to wear gloves for both her health and their health.

Cleanliness was not the only issue when dealing with agency workers. Some workers would have family members waiting in cars outside blowing the horn while they were working. One time, Nikki arranged for a worker to come Thanksgiving Day when her family was away. The worker told her on Wednesday night at 5 p.m. that she wasn't coming, when Nikki's family were already gone. Nikki also worried about whether an agency worker had skills,

And then you would show the procedure (for a particular care task) over and over and over and then you almost get the feeling that they are not getting it, so then my mom has to continue to do it (anyway), so they are not actually helping. And

then you take your bath every two or three days, but then you are still smelling (because they don't do a good job), so it's not comfortable.

I Need Help with Everything

Nikki describes the many things that her mother helps her with,

In my condition, I need help with everything. My mom is my complete life source. I need help from combing my hair, gargling mouthwash, to applying medical pads to the bottom of my heels, my bath. I take Insulin. I get two shots a day, and I have three meals. She prepares them all. She gives me the shots. She bathes me. I get my daughter or some outside friends or something when I want to be priss and leave the house...

I always have this feeling that my mom does so much for me. I can't give back. She can't rest. She's up from actually 4:00 (a.m.) to 4:00 (a.m.) and her day stops around 4:00 in the morning. She gives me laxatives and then she goes to the living room and kitchen for breakfast by 6:30 or 7:00 and then it's time to clean me up and bathe me. Then she gives me my shot and then all of my meds, all the ones you see up there. By the time she can lay down for two or three hours, it's lunchtime.

At about 12:00 or 1:00 she does the lunch thing for me. She gives me some more meds. Then if no one comes over or the phone does not ring or friends visit, I have a lot of nice friends, she can lay down to about 4:00 and then she is up to change me again. Oh, she catheterizes me, too. I have medical kits, my bladder, she has to empty twice a day and prepare me for the evening with my shots and dinner. So, my satisfaction comes in that her job is made easier or more pleasant. It doesn't take much to satisfy me.

On a small injury on my bottom years ago, an aide's ring scratched me because I have never had a bedsore, but it turned into one, so my mom keeps it under control. If I don't get out of bed in a few months, it will come back, so she tries the Duraderms (skin patches) and keeps it clean. She washes and creams my heels and feet to keep them from breaking down. I see a doctor once every three months, so she makes it possible for them to come into the house, and all of this helps me...

Nikki says that her mother washes a load of laundry a day in order to keep the house smelling clean and they also use air fresheners because her bedroom has a hospital atmosphere. Nikki thinks that hygiene and medication are the most important aspects of the care her mother provides for her. She needs hygienic care for her health and comfort

and her mother keeps track of her medications, keeps them in order, and knows what Nikki needs to take.

Sharon's description of what she does for her daughter during the day give a sense of how hard she works,

When the morning starts off, I get up real early to start taking care of her. I bathe her up give her breakfast, let her rest awhile, give her, her meds, she has umpteen of those. (At) about 12:00 or 1:00 o'clock, I give her a sandwich or something and in the afternoon I change her and straighten her up. Then I give her a few more meds and then give her her evening supper and make her comfortable....she likes looking at TV, so that keeps her company and sometimes she stays up at night on the telephone talking to her sisters and brother. I say my prayers and take my bath and I lay here on the settee and she hollers in here and tells me what to look at (on the television) and finally we doze off, the usual... Every day is about the same thing. I did it so much it just comes naturally.

Sharon has to do everything for her daughter. She feeds her daughter and if her other children are there they help by feeding their sister. Sharon describes the medical care and cleaning care she provides,

I have to do everything for her. I get up in the morning at 4:00 o'clock and give her medicine that she takes to move her bowels and in the morning I give her a suppository which helps out. I give her that about 4:00 o'clock in the morning, wait until about 7:00 and then I get up and clean her up. I do that on Monday, Wednesdays and Fridays...

(I) wash her hair about once a month. That's pretty hard to do, but I have a niece that comes in that's pretty close and we turn her around on the bed, put the bed flat down, run the bed kind of up and leave the rails on that side up... let the legs and let her head hang down. We get a stool or chair and bucket and we wash her hair. Other than that, I give her a bed bath mostly, but I can do that. I did that so much.

Her skin has been pretty good, not much breakage but I always have the pieces of stuff like a small curtain (Duoderm). It heals your skin. She has been fortunate not to have no bad (bedsores). If she do, I see it ahead of time then I take (the problem) to the doctor and have them bring her over there and they get her straightened back out, but they don't be real bad so they showed me how to do that so much that I keep (her skin in good shape). I takes it (Duoderm) off though for the skin to breathe, that's what they call it, I know the words. She's always got to sleep with something, like something soft under her heels so nothing will break

on the bed, that comes from washing the sheets and things. I don't put no strong detergent and that holds it pretty good... They have a doctor that makes house calls that take care of her feet. He's been coming for years, we make an appointment and he works it in.

The most difficult thing for Sharon is moving her daughter. She has learned how to stand and push her daughter's shoulder to start moving her.

Our Monthly Budget is a Bit Small

Nikki thinks that she and her mother did not ask for enough money or caregiving hours for her mother when they first developed their budget. Sharon is paid for 15 hours a week of caregiving, three hours a day Monday through Friday. When Nikki and her mother added hours, they went over budget and had to repay the money. Nikki blames her problems on her inexperience, "I guess I misunderstood that we could work and see how certain set of hours worked and then we could add more if we needed them." Nikki and her mother have almost repaid their overspending. Nikki says that she is not happy that her mother will only be paid for three hours of work a day, but it is better than nothing. Sharon is paid \$10 an hour. Sharon says, "It would be nice if I could get a little bit more, but I appreciate what I'm getting, because I wasn't getting nothing (before). Sharon does not need supervision because she has helped her daughter for so long that she knows what to do, "I just get on up and do it." Sharon used to wake very early when she drove a school bus so she is used to waking up early.

Use of the Cash Allowance; How This Program Helped Me

Nikki thinks that the money she and her mother can use for supplies has been the most help,

That's how this program helped me. See, it was getting the supplies that was really breaking my mamma. Like the personal things that I (use to) bathe, to wash, the deodorants, the shampoos, the lotions, the vaselines, all the little things

that keep your body up. Like I said, I have been paralyzed for 32 years. I think it's because my mom helps me. This program gives her relief. You know, she don't worry so much about financial things. It's not perfect. The budget is medium. It's about \$952....about \$1,200 or \$1,300 would be better, but it's what we didn't have (before)...

Nikki uses the money for supplies,

Clorox and Lysol, the expensive disinfectants, they are very expensive, alcohol and peroxide, deodorants, mouthwash, Efferdent because I have dentures, stuff like that, the washing pads. Now the diapers are covered by Medicare/Medicaid. The gloves are not covered. All different things that keep your house disinfected and smelling good, and to keep my body soft. Because if your skin is soft, you don't do the bedsores. If it is clean, you don't have the bedsores, and if you don't have the bedsores, then you are not embarrassed when people come around. My momma sees to that. And the laxatives, the Ducolax, all those over there are expensive. You have to get them every month and the mouthwash and mouthpiece for the medications, so you have to get medicines to heal it. It's just a constant thing. You are constantly buying, applying, and giving out, buying, applying, and giving out.

The Caregiver Relationship

Nikki says that she cannot repay her mother for all the care she gives and that she is an amazing woman. Sharon says that she and her daughter have a good relationship, "She worries about me and I worry about her." Sharon describes why she helps her daughter,

I like working and taking care of her because I want to see her happy, and she is happy considering what's wrong with her most of the time, and she very seldom gets depressed or anything. You'd be surprised how she can handle (things). When the phone rings, I put it to her ear, but certain things she can take care of the call and make connections. She uses the phone with the tongue. She can press the button and she has a lot of her friends when she was going to school years ago. They go away but when they always come back. They always call and come to see her and she has a friend and a nurse at the hospital and she always calls and visits and they been friends ever since the accident and before.

Sharon says that she enjoys being with her daughter at night because they talk all the time.

Caregiver Experience

Sharon learned how to take care of her daughter over the years when she stayed with her in the hospital. In fact, people who want information about health matters often call Sharon for advice because they think, “we know everything about sickness.” Sharon also helps other patients whenever she was with Nikki in the hospital because she would hope that others would do the same for her daughter.

Nikki feels that trustworthiness is the most important qualities of a good caregiver. A caregiver must also have some skills. Sharon thinks that a caregiver needs to be both good hearted and a family person.

Problems with the CDC Program

Nikki comments that she does not want to be ungrateful, but she feels that they need more money every month and she should pay her mother for more hours. She and her mother also had a difficult time repaying the money that they overspent for caregiving hours. Nikki feels that her budget should be revised,

Like if they would ask me and my momma again, you know when we first did the interview (about the budget), the things that we have to spend and the things that we have to do, then my budget right now would be a little higher than the \$952, but when we were trying to figure it out, you don't never think of everything until you go to the doctors.

... the supplementary diabetic drinks and stuff are very expensive... I didn't consider that, you know. I didn't consider the head and shoulders and the body deodorant and the mouthwash. I was only thinking the medical supplies. That's the only thing I would consider. I would increase the budget a little. I know they can't give us eight hours, but I would like to see... two in the morning, two in the afternoon and two in the evening. I would need a budget around that. Three hours (a day) is really not enough, but I'm thankful for it.

Nikki says that if she could do her budget again she would ask for \$400 to \$500 more, “I could be comfortable with a \$1,300 budget.”

Benefits of the Program

Nikki describes how the CDC Program has helped her,

Quite frankly, it is the finances because that's where we were hurting. Everything else, my mom and I had worked out over the years. We had over 30 years of time to make this work for us, and my kids, if my mom gets sick, they step in when I need to go out somewhere. The extra finances, and the medical supplies, and there are so many things that can't be paid for by Medicare and Medicaid, so actually it's the finances are the most appropriate. That's the best thing we needed.

Nikki says that the program gives her peace of mind, "This is the one thing that I can help them (her family) and help myself at the same time." Using the cash allowance also allows Nikki to keep her dignity because she does not have to apply to use it for every single thing she needs. Nikki keeps track of the budget and paperwork herself.

Sharon thinks that the benefit of the program is that she can stay home with Nikki and still get paid rather than having to work driving a school bus, which she did for 15 years. Sharon also is grateful for the money because it allows her to keep Nikki at home, where she is happy, and out of a nursing home.

Consumer Story 24

Dwight Brown is a 9 year-old white boy with cerebral palsy and developmental disabilities, who lives with his mother and fourteen year old sister Gwen, in a middle class suburban home near Miami. His mother Marsha is his representative and his grandmother Angela is his primary caregiver. Dwight's grandmother lives across the street from his mother's home. Marsha is an agency worker. Dwight is wheelchair bound and requires constant care. The interview was conducted in Dwight's grandmother's home. Upon arrival of the interviewers Angela called Marsha and she walked from her home across the street to her mother's home, where Dwight was at the time. Dwight was casually dressed and neatly groomed. He seemed very interested in the interview process and made several attempts to provide input although it was difficult to understand what he was saying, his mother provided interpretation. The family members were all very close. Marsha and Angela included Dwight in their playful conversation regarding his care and his disability. He seemed to respond very well to this and was active and in great spirits for the duration of the interview.

People He Knows

Family members are an important part of Dwight's life. In addition to his grandmother, his uncle helps care for him at night. Marsha says that this gives her mother Angela a break, the uncle enjoys having some extra money, and she appreciates his help transferring and lifting Dwight. Marsha likes it when he comes to help at night because, "I don't have to do so much lifting then." Marsha gets respite care for Dwight from her sister and even Dwight's godmother has helped. In addition, Dwight's sister,

Gwen, “his idol,” is a great help, “everybody he has had (help) are people he has known, which is good.” Marsha thinks that it is very important to have a representative and caregivers who are family because of the “love connection” they have with Dwight,

They are going to make sure that the person has the very best and all their needs are met where somebody else that is not a family member, they might be like more lax to make sure that it gets done. They don’t understand. See when you live in a family with a disabled person, I have my son plus my aunt, who is autistic,...you live with that day in and day out, and you just know what you have to do for them...

Marsha worries that someone who was not related would not put the needs of the person with a disability first.

Angela says that the family is close because “Italian families stay together.” She describes how wonderful Gwen is with her brother Dwight,

She’s wonderful with him. People are amazed at her, you know. Even when my husband was ill, she helped tremendously with him, too. Gwen was very close to my husband, Mike, and when he was dying and everything, and at the hospital, and he had the life support and tubes, this girl would come in there and she was only twelve years old, and in there she learned how to do everything; the nurses taught me how to do everything since we were taking him home since I wouldn’t put him in a nursing home. No, I would not put him in one of those places. And when we got him home here, she was here, she would just go in there and she’d help feed him, she knew how to flush the tubes out, she’d help him change the trach.

Yes, she was very mature...she’s marvelous with Dwight, she really is. And sometimes, too, with Dwight, Gwen wants to play with her friends, too. We say “Dwight, you’ve got to give Gwen her own space. She needs to have a few minutes to play with her friends.” But she does good.

He Has Lost a Lot

Dwight has cerebral palsy. He must use a “stander” to help him stand during the day, but he cannot stand on his own or take any steps. Marsha explains that Dwight had surgery two years ago for a hip dislocation after which he lost his ability to take steps.

She regrets allowing the doctor’s to operate on her son because he lost so much after the

surgery. It has been several years since this happened and Marsha still feels regret that she did not listen to her gut feeling, “One thing I tell people is if you don’t feel right about it, then don’t do it. (Doing) nothing is not going to hurt anything more.”

Marsha also discusses how the hip surgery hurt Dwight,

That was very hard on him. It was very painful, and he was in a body cast from his waist down, and so that took a lot of help and they put plates in his hips and they didn’t work out. So last year, they took them out, thank God, but it was very painful and we were able to handle it. Unfortunately, I’m very experienced in that kind of stuff right now, but it was the best thing taking out those pins that the doctor had put in. It was very painful, you know; the pins in his hips for some reason didn’t help him. Usually with CP kids it will help in aligning the hips, but it made it worse with him. So he’s doing great now, as you can see. He’s a good eater; he doesn’t have any health problems at all.

Enrolling in the Program

Marsha heard about the CDC Program at the yearly “Family Cafe,” a weekend for children with disabilities and their parents to hear about new programs, new assistive devices and other information useful to the families who participate. Marsha looks forward to going every year because it provides her with a break. Respite care is available for the children so parents can attend the information sessions.

I Can Handle Things for My Son

Marsha has a unique point of view about her previous experiences hiring agency workers because she is herself a personal care attendant for respite care who works for agencies. She was interested in hiring her own workers because she feels able to handle care arrangements for Dwight, and she was not happy with former agency workers,

I work for agencies, but I am a little bit more dedicated, and I don’t give up my families. Like these people come into it. They come to do a job and they are like they can’t handle it and they leave. That’s not good for a child. You need to have (consistent care), especially for a child and even an adult that’s disabled because it’s different. You need to have a set person that they can rely on every day or at least maybe three. It could be between three or four set people a week. At least

they know that these people are going to be there for them, not people are going to come in and they are going to see you twice or three times and leave and then have another person come in and do the same. It's not consistent. It makes them nervous. It makes them upset. Don't forget, when different people come in, they are handling changing most of these people, diapering, and personal stuff, and you know they have feelings, too. They are not comfortable with showing themselves to everybody.

Marsha was dissatisfied with the turnover in agency workers which she thinks is bad for a child with a disability. She thinks that some agency workers find that they cannot handle the work. Marsha does not like having different people in her house everyday and she worries that when you depend on an agency they may not have a worker to send to you. She also had a worker she liked, but who was undependable.

Sharon discusses the disadvantages of an agency worker. She describes an experience she had with a paid worker when she was caring for her mother who was in the hospital for cancer treatment, "She gave her wonderful care, but it was strictly by the book." If Sharon was going to be late to see her mother she would ask the agency worker to stay, "She would stay, but if she couldn't, she would leave."

Lifting is a Big Issue

When she describes what Dwight needs help with, Marsha stresses that he is wheelchair bound and weighs one hundred pounds. In addition to toileting, transferring is a big issue,

When he is sleeping he is all right, but you know getting him up and getting him ready, the lifting is a big issue. Lifting is my biggest thing because I need help. It's definitely two people. I used to be able to do it by myself. I can't anymore. It's really, really hard. Sometimes you need three people. It's hard because he's dead weight.

Sharon goes to Marsha's house in the morning to help Dwight get ready for school, what Marsha calls the "morning detail." She gets him up, changed, and dressed,

feeds him breakfast and gets him to the bus stop for school. Dwight can feed himself if his food is separated. Sharon also reads to him and helps him with homework. Lifting Dwight is the most difficult thing that Sharon does,

The lifting sometimes (I) worry about those things, like if there's a fire or something. God forbid, if he's in his bed and we couldn't get to him. You always think that even though you say it's not going to happen, you always think of those things. It's not that a fireman could run in and try and lift him... he's dead weight. We can lift up you or me, but when he's literally dead weight, it's like double the amount of weight. (It's) very hard, because I'll say, "Dwight," sometimes if I'm going to transfer him out of the chair and, if he has his left arm (free) which is good (he has some use of his left arm) and I'll say, "Dwight, put your arm around my neck and give me a little help." He gets lazy. He doesn't want to do it. He can do it. So one day, I was transferring him out of the chair. I pulled the chair right up the bed so I could just pull him out and flip him on the bed so there's no problem. So I said to him, "Dwight, mom-mom's doing this by herself, now you have to help me, you have to help me." "Don't drop me." "But you'll have to hold onto my neck. You can do it." And he used his bad arm and he held on to me.

"See, you can do it if you want to do it." What I do is I grab him and slide him, and the bed's right there. But he was holding on because I kept saying, you know, "you've got to do this." "Don't drop me, don't drop me." I said, "Well, then you hold onto my neck and you can use it; you can use your arm." It was really funny, and then he gets lazy. Most of the time he doesn't (help). He's the king here. He's King Dwight, right, honey?

At the end of the day, Sharon helps Dwight with a snack after he returns from school. She also helps him get ready for bed, lifting him out of the wheelchair, brushing his teeth, and getting him in the shower, now that Marsha has a "handicapped shower." Before they had this shower, bathing him was a "nightmare." Sharon also accompanies Dwight to physical therapy to help with transferring him out of the car. Sharon works at a department store where she has flexible hours. She has been on family leave for several months because she is at home caring for her autistic sister.

Schedule

It is very convenient for Marsha that her mother lives across the street and can walk over to help whenever she is needed. Sharon usually helps from 6 to 8 a.m. Monday through Friday and 8 to 10 a.m. on Saturdays as well as other times during the week. Marsha may call her when she has to lift Dwight or put him in the stander. Sharon is paid for 20 hours a week. Marsha says that their care of Dwight will never end. If he did not have a disability he would be dressing and feeding himself, but “it’s going to be like this for the rest of my life and his life.” Sharon says that care of Dwight is an all-consuming part of her daughter’s life, “since he was born he started therapy, and she has never faltered on it. Every day of his life for nine years... not many women could continue that pace.” Marsha supervises Dwight’s caregiving and hires the caregivers. Sharon says that she and her daughter discuss Dwight’s needs,

My daughter is with me a lot, I don’t know if it’s called supervision. If I see something amiss with him or something, we always discuss it. Like I noticed the last few weeks he’s been eating excessively, and that’s a worry to us because he’s so big, but then we figured he’s in a growth pattern now. He’s going to shoot up and he’s very hungry all the time! Yeah, he’s gorgeous; he’s just so big and so heavy...

Pay

Marsha pays \$10.75 an hour to Dwight’s caregivers. Marsha would like to raise the pay and plans to talk to her consultant about revising the budget. Marsha chose the pay scale because of her experience as a personal care assistant. She knows that caregiving is hard work and the workers need to be paid well. Sharon feels that the pay is fair although she works more than she is paid for because she is his grandmother. In fact, she was uncomfortable with being paid at first,

To be honest, I thought getting paid for taking care of my grandson doesn't seem right, (but) then (Marsha) would have to bring in a stranger. So I got over the guilt and it's just part of my life now and everything.

I Have Always Been a Part of His Life

Sharon has been with Dwight since he was born at a birth weight of 2lb 8ozs. Marsha and her children lived with Sharon until 4 years ago when they moved across the street. Sharon is close to Dwight. She says that they are "bonded, I'm his mom-mom. This is his house." He asks her about everything she does and always wants to help her cook. Sharon lets him help as much as he can, "I let him put the pepper on or something." Sharon feels that she gives Dwight "tender loving care, extra care" because she's family. For Sharon, Dwight "is a joy and we just want the best for him and a having a chance at a normal life." Sharon has cared for her husband, her mother, and now her sister, as well as Dwight.

Personality is Number One

Marsha has a clear idea of the characteristics needed for a good caregiver,

Personality is number one. Personality, appearance, qualifications. I'm not looking for someone that has to have a bachelor's to help change a diaper or lift somebody. They know what they are getting into and they are going to be responsible and be dedicated and not be somebody that has jobs and they are in and out of jobs. They have to know that this is a job. This is really truly a job. You are getting paid for it. It is a job that you have to have your heart in and love, and it is also very physical. When you see those kids and you are working with them, you have to want to go back to the children or even those adults because we forget that our children turn into adults who are still our children. They just look bigger.

Sharon thinks that a good caregiver needs patience. If a caregiver is "not blood," they need to learn to like or love the child in order to do a good job. Sharon gives an example of a child that Marsha cares for, a little girl with severe developmental disabilities, who drools. When she comes to their house and they all go out Sharon says

that people stare as they sometimes stare at Dwight. Sharon thinks it is important to remember that drooling, or being in a wheelchair, or needing to be diapered as she did for her husband and mother and now Dwight “are no big thing. You just do it and don’t make an issue of it” so as not to humiliate people.

Use of the Cash Allowance

Marsha uses some of the cash allowance for diapers which are very expensive. She buys wipes, chucks, rash medicines, and lotions. She uses coupons and tries to shop at sales so she can buy extra packages of diapers. Marsha is also working with the consultant to get ramps into her house. She just replaced the ramp into the bathroom. This is especially important because Marsha is looking ahead to her son’s adult life, “I am making my house handicap accessible and I am looking at (the) long-term.” Marsha buys the pads used with the electric stimulation machine for Dwight’s muscles and pays for Dwight’s massage therapy. The consultant has helped Marsha with the paperwork and given her guidance about use of the cash allowance.

Problems with the Program

The paperwork for the program was confusing and overwhelming to Marsha at the beginning, but she feels that it is better now and would recommend other parents to enroll in the program for their children.

Benefits of the Program

Marsha likes to handle things for her son as his mother and caretaker and she likes hiring who she wants,

I am able to have my family members and my friends that have known Dwight since he was a baby (as caregivers). The thing is that I like the fact that if I have to, I can hire somebody on the outside and interview them. I read people very well, so I can look at them and say (whether they are good). I want to feel

comfortable with this person coming into my home. I want to let them know that this is what you have to do, this is what it takes, and if you can't do it... I don't even want to say let them try it because I want consistency with him.

I am looking into his adult (life). I mean I hope this program stays until he is an adult because I don't know what it is going to be like when he is an adult, but I know I want him home as much as I can. I don't want to put him away into a nursing home or something because I think in the long run, this does save the state a lot of money because nursing homes cost probably ten times as much, and you don't get the care that you would get at home from people that love you and know you.

Hiring her own caregivers allows Marsha to have more flexibility with the caregiving times. She also likes having a choice, being in control, and having a say,

I like overseeing. He's my child. He's my family. I want to make sure that he has the very best, and I feel like I'm in control now. I am in control. I don't have somebody else telling me, oh, well, this is it. You know, that's not his family member. They don't understand where you are coming from. They may be just a worker. This gives you control and makes you feel like you have a say.

Marsha also feels that she is more relaxed since she and her son have been on the program,

I am not as stressed about the lifting (because) I had help and I'm still stressed, I guess. You will always be stressed with a child, but I feel like there's an option. I have options now. I try to work around things.

Discussion

The consumers interviewed in Florida included children with disabilities under the age of 18 (#11, 12, 18, 19, 20, 22, 24) and children with disabilities who were over the age of 18 and cared for by older parents (#8, 9, 13, 17, 21). Their experiences and needs differed from those of the other consumers in the program (#1, 2, 3, 4, 5, 6, 7, 10, 14, 15, 16, 23). In Florida, parents of children with disabilities were able to act as representatives and paid caregivers at the same time.

The consumer stories from the Consumer Directed Care program share a number of themes. In this section, the caregiver relationship, the skills and qualities of caregivers, problems when hiring family caregivers, the physical problems caused by caregiving, previous experience with agency workers, the relationship with the consultant, the alternate uses of the cash benefit, problems with the program, and benefits of the program are discussed.

The Caregiver Relationship

Consumer Directed Care consumers hired both family and non-family caregivers. Consumers had a variety of different relationships with their caregivers. Mothers were important as caregivers (# 8, 9, 17, 21, 23). Ms. Cannon (#23) has been cared for by her mother for 32 years since she was paralyzed in a car accident. She describes her mother as her “complete life source” and is grateful for all the care she provides. Grandmothers also provide care (#12, 18, 24). Grandfathers are caregivers, too (#11). Paul Farmer’s grandfather works as his caregiver while his grandmother acts as his representative. Sarah Sullivan (#12) is an 8 year old girl with cerebral palsy. Her parents rely on Sarah’s grandmother for care half of the year when she is in Florida. Daughters are caregivers

(#2, 4, 15, 16). Mrs. Lynch (#15) is cared for and protected by her daughter, who will not allow the manager of the adult living community to evict her mother because of her incontinence. Sons are caregivers, too (#3, 5). For example, Mr. Newman's (#3) son and his wife have cared for him for twenty years, the last seven years through his Alzheimer's disease. Other family members are also caregivers. Ms. Dunlap is cared for by her sister (#7) and her sister's family. Mrs. Bennett (#14) is 98 years old and is cared for by her granddaughter with help from her grandniece and a non-family caregiver.

Several Florida consumers hired non-family caregivers (#1, 10, 13, 14). Mr. Joyner's non-family caregiver (#10) took a pay cut to keep working for Kent Joyner because she thought it would be better for him to have consistent care. Family friends and community acquaintances are also hired as caregivers (#6, 19, 20). Jay Andrews (#19) is cared for by a non-family caregiver with teaching experience, who Mrs. Andrew's met through a babysitter.

Many consumers received unpaid caregiving from family members in addition to paid care through the program.

Problems When Hiring Family Caregivers. While most of the consumers and representatives focused on the positive aspects of hiring family caregivers (#3, 7, 8, 9, 11, 12, 15, 17, 18, 21, 23, 24) five consumers and representatives described the problems they have with hiring and supervising family caregivers (#2, 4, 5, 14, 16). Susanna Burris (#2), who cares for her mother, says that it is not possible to provide both emotional and physical care to her mother at the same time. She is exhausted and depressed by her caregiver role. Mrs. Morris (#4) hired her daughter, who is not yet 18, as a caregiver. She says that she and her daughter have a difficult mother-daughter

relationship and that her daughter cannot wait to move out when she is 18. The consultant does not think that the daughter is responsible and does not always provide the care she should. Mrs. Erdman (#5) hired her son as a caregiver. She is very happy with his work now, but had problems at the beginning with him trying to take advantage and not providing care. She wrote a schedule and list of tasks so her son's responsibilities were clear and she continues to be strict with him. Mrs. Bennett's granddaughter (#14) hired family members in the past, but she says that they always think they know best and are difficult to work with. Mr. Beal (#16) hired his daughter as a caregiver and they have an ongoing, negative relationship and conflict over the money she receives as pay. His previous caregiver was his granddaughter and they also had conflicts over money. According to Mr. Beal's daughter, other members of the family took sides with Mr. Beal over the money conflict.

The Skills and Qualities of Caregivers

Caregiving is an important aspect of the experience of consumers in the program. Both consumers and caregivers have clear ideas about what makes a good caregiver. While there were a variety of skills and characteristics mentioned by the 24 consumers and their caregivers, three characteristics were particularly important; honesty and trustworthiness (#1, 6, 10, 13, 14, 15, 23), being pleasant (#1, 4, 5, 6, 8, 14, 15, 24), and patience (#4, 8, 11, 15, 17, 18, 20). Mr. Joyner (#10) is especially grateful to have an honest careworker after a previous agency careworker stole from him. Mrs. Lynch (#15) was seriously hurt by an agency careworker who pushed her down and took money from her. Consumers also value a pleasant relationship with their caregivers. Mrs. Brown (#24) thinks that her son Dwight does much better when he has caregivers who care

about him personally. Patience is also an important characteristic for a caregiver, according to Florida consumers. Mrs. Aguilar (#20) values the kindness and patience shown to her daughter Bonnie by a non-family caregiver the family calls “Tia” or Aunt. Mrs. Aguilar has two children in the CDC program and a calm, responsible caregiver is very important to her and the children.

Some of the other characteristics mentioned as important for a caregiver include flexibility (#4), cleanliness (#5, 23), hardworking (#5), consistent (#13), and dependable (#14). Even though dependability was not mentioned explicitly, it is important to consumers because they often mentioned dissatisfaction with their previous agency experiences because of undependable agency workers. While Mrs. Brown (#24) says that caregiver’s “don’t have to have a bachelor’s to change a diaper or lift people,” other representatives mentioned concrete skills that are important. Such skills include sign language for the caregiver of Ms. Covas (#8) who cannot hear or speak, and knowledge of CPR and knowing when to call 911 for Mrs. Aguilar (#20) who has two children with disabilities in the program.

Physical Problems Caused By Caregiving

Caregivers and representatives spoke about the injuries they sustained while caring for a consumer (#6, 8, 14, 18) and difficulty with lifting consumers (#2, 7, 12, 23, 24). Mr. Trappani’s mother (#6) had a serious fall and could no longer provide the physically demanding care her son, who has muscular dystrophy and is a quadriplegic, required. Mrs. Covas (#8) fell with her 37 year old daughter and describes how she needs to help her daughter become independent or find another living situation before she becomes exhausted. Mrs. Covas is also watching her daughter’s weight so she does not

become too heavy to lift. Mrs. Bennett's (#14) granddaughter has a bad back as a result of a fall in the shower when she was helping her grandmother. She still helps Mrs. Bennett, but cannot do heavy physical work or help her with showers. Yolanda Benevides' grandmother (#18) is kicked repeatedly by her granddaughter, once so seriously on a breast that she had to have a mammogram after the swelling subsided.

Caregivers find lifting consumers to be very difficult (#2, 7, 12, 19, 23, 24). Mrs. Burris (#2) often has to stay in bed because her daughter cannot lift her into a bedside chair. Ms. Dunlap's sister (#7) describes transporting her sister to the doctor's office as her biggest problem because her sister is so difficult to transfer into the car. The Sullivan's daughter, Sarah (#12) has just started to use a power wheelchair, which at 300 lbs., is impossible to lift and difficult to transport. Mrs. Andrews (#19) was injured in a car accident before the program started and was no longer able to work with her 7 year old autistic son as she had before. Mrs. Cannon (#23) provides total care to her 53 year old quadriplegic daughter around the clock. Mrs. Cannon is in her seventies and has her own health problems, but she says that the hardest thing she does is move her daughter. Mrs. Brown (#24) has difficulty lifting her son Dwight who is nine and now weighs 100 lbs. He has cerebral palsy and has only partial use of one arm so he is very difficult to lift. She pays her brother as a caregiver so he will help with lifting and has to have at least two people to help transfer her son.

Previous Experience With Agency Workers

Florida consumers described their dissatisfaction with their previous experiences with agency care. A number of consumers disliked agency workers because they were not reliable (#2, 5, 10, 14, 23, 24). Susanna Burris (#2) could not keep her job at

WalMart because agency workers never arrived on time so she could leave for work. Mrs. Erdman (#5) complained that agency workers would not come when she needed them to arrive and would often call multiple times to change their hours. Sometimes they did not show up. One time, an agency supervisor had to come help Mrs. Erdman shower because there were no agency workers available. Kent Joyner (#10) has M.S. and needs help early in the morning when he has energy. Agency workers often arrived late and it was a worry because he “needs to know help is coming.” Mrs. Bennett’s granddaughter (#14) almost lost her own small business as an accountant because agency workers did not come on time and she could not leave to meet clients. Mrs. Bennett’s granddaughter (#14) mentioned that in one two week period, her grandmother had a different agency worker every day. Mrs. Bennett is 98 and requires personal care and help with showering. Her granddaughter felt that her grandmother needed more consistent care that provided her with some privacy and dignity because of her age and her modesty. Ms. Cannon (#23) receives care throughout the day on a strict schedule. When agency workers were late her mother had to begin providing the care. By the time the agency worker arrived some of the most difficult work was already finished. Mrs. Brown (#24) also objected to her 9 year old son being changed and dressed by many different agency workers. She feels that children with disabilities need consistency and structure and personal privacy and dignity. Mrs. Andrews (#19) also said that her 7 year old son Jay, who is autistic, did not do well with many different agency workers. Jay needs to have structure or he “backtracks,” and becomes less functional.

Some consumers disliked having strangers in their homes (#2, 5, 6, 14, 24). Mrs. Trappani felt very uncomfortable with people she did not know coming into her home to

care for her son Richard. Susanna Burris (#2) said that her family found some of the agency workers to be “weird” and suspected them of using drugs. One agency worker told Mrs. Burris that she invented a “bug zapper” to destroy bacteria. Several agency workers had boyfriends who Susanna Burris found threatening. Ms. Cannon (#23) describes agency workers whose family members would sit outside her home in cars and blow the horn impatiently so the worker would hurry and leave for the day. Mrs. Erdman (#5) claims that one agency worker told her that she had faked the C.N.A. training and was not qualified to work.

Two consumers were concerned by the lack of cleanliness of agency workers (#16, 23). Mr. Beal (#16) was disgusted when an agency worker emptied dirty water from cleaning the bathroom into his kitchen sink. She then poured cleaning water full of chemicals on his lawn. Nikki Cannon (#23) said that she had to remind agency workers to wear gloves when they worked with her. She also said that she received substandard bed baths from agency workers. Two consumers had problems with dishonest agency workers (#10, 15). Kent Joyner (#10) had a worker steal from him and Mrs. Lynch (#15) not only had an agency worker steal money from her, but she was pushed to the floor and had to be hospitalized for several days after the incident.

Several consumers hired former agency workers (#1, 10, 14) whose work they found satisfactory.

Relationship with the Consultant

Florida consumers had varying amounts of contact and interaction with their state consultants. Consumers and representatives made both positive (#1, 4, 5, 6, 8, 11, 15, 17) and negative (#12, 13, 16) comments about their consultants. Consultants were

positively described as guides to the program who provided access, help, and resources. For example, Mrs. Covas (#8) said that her consultant spoke Spanish and was always available to her. Mrs. Gabriel's (#17) state consultant helped her find high quality respite care for her daughter. The Sullivan's (#12) had a negative opinion of their consultant. They thought the consultant acted as one more middleman between their daughter and needed services. The Sullivan's were frustrated because they thought that they were teaching the consultant her job. Mr. Beal (#16) was angry at his consultant who intervened between a conflict between him and his daughter over the use of her caregiving pay. Mr. Beal thought that the caregiver did not listen to him and patronized him because of his disability.

Alternate Uses of the Cash Benefit

Florida consumers used the cash allowance in many ways in addition to pay for caregivers. The cash benefit helps consumers, consumer representatives (parents of children with disabilities use the money to pay for their children's needs) and caregivers. Consumers used the money for personal care items (#1, 3, 7, 8, 11, 14, 15, 17, 22, 23, 24). Diapers are very expensive and were mentioned frequently as an item paid for out of the cash allowance (#11, 12, 15, 22, 23, 24). Several parents of children with disabilities liked the fact that they could save money by using coupons when they bought their own diapers and get more supplies for their money than possible when receiving supplies through the state. Disinfectants and cleaning supplies were also mentioned. Ms. Cannon (#23) needs disinfectants for her room, air fresheners, over the counter laxatives, and many supplies to keep healthy as a quadriplegic. Ms. Dunlap's caregiver (#7) uses a tube of Neosporin a week at \$7 a tube to control her sister's skin rashes, the cash benefit is

important for them to be able to supply the needed items. Two parents of children with disabilities used the money to pay for dental visits for their children (#8, 17) and one paid for the repair of broken glasses (#17). Paul Farmer's grandmother (#11) used some of the money to pay for clothes for her 10 year old grandson who was outgrowing his clothes quickly. Consumers also used the money for medication (#3, 5) oxygen (#7), and supplemental nutrition drinks (#12). Mrs. Erdman (#5) uses her entire cash allowance to pay for one pill.

Consumers used the cash allowance to buy assistive devices (#4, 7, 8, 11, 12, 13, 22, 24) and pay for home modifications (#10, 12, 24). Mrs. Jansen (#1) mistakenly thought that she could not use her cash allowance to pay for grab bars because they were not "personal" items. Mrs. Morris (#4) buys supplies for her scooter and is saving her money for a Medic Alert system, for example. Ms. Dunlap's family (#7) used the money for a hospital bed. Mrs. Covas (#8) and the Sullivans (#12) each bought a bed for their daughters. The Sullivans bought a bed that looks like a child's bed, but functions like a hospital bed. Paul Farmer's grandmother (#11) bought an adaptive bicycle for Paul. It provides exercise and back support and can also be used as a tricycle. The Sullivans (#12) have bought many assistive devices for Sarah who has cerebral palsy, is quadriplegic, and uses a power wheelchair. They used the cash allowance to buy adaptive spoons and plates, and a slant board and writing instruments for their daughter at school. The Connolly's (#13) use the cash allowance for costs associated with upkeep of the power wheelchair their son Adam uses. They also pay for repairs that Mr. Connolly cannot do himself, to the van they use to transport their son. Jenny Hollins parents (#22)

bought her a helmet for protection. Mrs. Brown (#24) buys pads for the electric stimulation machine her 9 year old son Dwight uses during therapy.

Several consumers use the cash allowance to build ramps. Kent Joyner (#10) had a ramp repaired so he could leave his apartment. The Sullivans (#12) built a ramp for Sarah's grandmother's home so she could visit. Sarah's grandmother is saving to have her home's doors widened. The Sullivans said that they would never be able to use Medicare money to adapt Sarah's caregiver's home, but that it is important for their daughter to be able to visit her grandmother, and this is a big help to them because it gives them a break, too. Mrs. Brown (#24) had a ramp built in her bathroom and is gradually modifying her house for better access for her son Dwight. She is looking to her son's future use of the house and his needs as he gets older. Kent Joyner (#10) used some of his cash allowance to pay for termite extermination.

Florida consumers use the cash allowance to pay for a variety of other items and services as well. Several parents of children with disabilities mentioned that they paid for therapy for their children that was not otherwise covered (#8, 9, 24). The Arroyos care for their 27 year old autistic daughter Marilena. They use the money to pay companions to stay with her and work on socialization. They also pay for massage therapy, music therapy, and plan to use the money for psychological counseling. The Covas family (#8) also paid for psychiatric counseling to help them deal with their daughter's extreme dependence on her mother. Mrs. Brown (#24) pays for therapy for her son Dwight which she has been committed to since his birth.

Mrs. Lynch (#15) pays for one day a week at adult day care and the \$5 transportation fee. Mrs. Scofield (#21) pays for van transportation for her son Ian 5 days

a week. She drives him to work in the morning, but has more flexibility in her schedule because he is brought home in the afternoon. Mrs. Gabriel (#17) pays for her daughter Lynnette's summer camp fees and club activity fees with the cash allowance. The summer camp and club events provide Lynnette with a social life and provide her mother some respite, something that Mrs. Gabriel says she never takes for granted.

The cash allowance helped two consumers' families in their work situations (#2, 14, 23). Susanna Burris (#2) could no longer work because she provided care for her mother. The cash allowance offset the loss of income and made it possible for her to stay home and kept her mother out of a nursing home. Mrs. Bennett's granddaughter (#14) was able to keep working because she hired a dependable caregiver for her grandmother's care. Mrs. Cannon (#23) was able to provide care at home to her daughter and did not have to work outside driving a school bus which she had done for many years. Mrs. Cannon thought that the cash allowance allowed her to keep her daughter out of a nursing home.

Respite care was mentioned as an important service purchased with the cash allowance (#2, 3, 11, 12 13, 14, 17, 21, 22). The Connollys enrolled their son Adam (#13) in a center which provided them with a break and gave their 26 year old son his own "social world." Mrs. Gabriel (#17) gets psychological and emotional relief because she knows she can get respite from her daughter's care and provide her daughter with a safe, enjoyable break, as well.

Florida consumers use the cash allowance in a variety of ways. Parents of children with disabilities are especially conscious of the therapy, assistive devices, and

supplies their children need and the most efficient and inexpensive ways to acquire these goods and services.

Problems With The Program

Consumers described problems with the program including the large amount of paperwork (#2, 6, 8, 10, 24) and accounting problems such as reading the financial statement and keeping track of the balance of the cash plan (#4, 9, 10, 11, 12, 18). The accounting difficulties resulted in overspending of the cash plan (#15, 17, 23) which was a hardship to repay, and difficulty keeping track of caregiver's hours (#2, 14). Two consumers felt they received conflicting information about the use of the cash plan (#2, 16). One consumer did not like the fact that the consultant had the final say in the use of the money (#12). A caregiver complained that the pay did not include any benefits (#2), such as health insurance and retirement.

Mr. Joyner (#10) found the paperwork overwhelming. A number of consumers and their representatives agreed. A bigger problem was the confusion with the accounting in the program, especially unreadable monthly statements. Mrs. Sullivan (#12) is an accountant who keeps a spreadsheet of the allowance and expenditures. She said that she could not even read the monthly statements, and the balance never matched hers, which she knew to be correct.

Three consumers overspent on the cash plan with caregiver's hours. This money had to be repaid which was very difficult. Ms. Cannon (#23) said that she mistakenly thought that there was more flexibility in the cash plan with caregiver's hours than turned out to be the case. She thought that the cash plan could be adjusted easily if more hours were needed. Instead, she overspent the cash plan with caregiving hours and had pay it

back. Ms. Cannon blamed the problem on her inexperience in estimating what she needed in caregiving hours and supplies at the start of the program. Mr. Beal (#16) disagreed with the consultant over the proper use of the cash and Mrs. Burris' daughter (#2) checked with a program representative from Washington D.C. because she did not think the consultant was correct about use of the money. She also had to quit her job to care for her mother, but she felt that the caregiving pay did not cover the health benefits and retirement benefits she no longer received. The biggest problem with the CDC program seemed to stem from start-up problems with accounting procedures and paperwork that were improving by the time the Florida consumers were interviewed.

Benefits of the Program

While consumers gave a variety of answers about the benefits of the CDC program, the importance of financial help, respite care, control over care, the flexible use of the cash allowance, and choice were the most frequently mentioned benefits. Consumers liked the program and would recommend it to their friends. Several consumers asked the interviewers if the program would continue and Mrs. Brown (#24) hoped that the program would be available for her 9 year old Dwight when he was older, because there are not many services for older children with disabilities.

The financial help was appreciated by a number of consumers (#2, 4, 5, 7, 9, 12, 21, 23). Both Mrs. Morris (#4) and Ms. Cannon (#23) needed the financial help to buy personal supplies which are necessary for their health and hygiene. Two caregivers (#2, 23) can stay home to care for their family member because of the financial help, which, in both cases, keeps the consumers out of a nursing home. Four caregivers (#4, 5, 7, 15) said that the caregiving job with the program was an improvement over other work. Mrs.

Morris' daughter (#4) said that because she was paid her caregiving was "not just favors here and there all over the place." Mrs. Erdman (#5) said that she got more work from her family caregiver than she did from agency workers. Her son liked the work because it was less stressful when you worked for someone you know. He appreciated the pay because he used it for his monthly car payment. Ms. Dunlap (#7) appreciates being able to pay her sister for care because then she does not feel like such a burden to her sister and her family. Mrs. Lynch's daughter (#15) said that receiving money for caregiving motivated and encouraged her to provide even more care than she was paid for.

The cash allowance allows consumers and their representatives to pay for respite care (#3, 11, 12, 13, 21, 22). Adam Connolly (#13) has recently made great progress after his medication was adjusted. His family is able to pay for him to attend a daycare center with the cash allowance. He has his own social world and his mother gets a break from caregiving which helped the whole family. Mrs. Scofield (#21) was grateful for the financial help because since her son did not need the services of an agency worker she did not realize that he was eligible for personal care services. The ability to pay for a friend to supervise her son has helped her tremendously and allowed her to do things outside of the house.

Control over care and expenditures were mentioned as benefits of the program by a number of consumers (#3, 5, 6, 8, 9, 10, 11, 12, 14, 15, 16, 17, 19, 23). Control of caregivers' hours was mentioned by three consumers (#5, 10, 14). Mrs. Erdman (#5) felt unwell in the morning and cannot use help before early afternoon. Agency workers always wanted to work at 8 a.m. When she controlled her care she was able to decide the caregiving hours that worked for her. Similarly, Mr. Joyner (#10) needed a caregiver

early in the morning when he had enough energy to benefit from the care. He hired a caregiver for early hours on the program. Mrs. Bennett (#14) needed help in the late morning and again in the late afternoon. Her granddaughter was able to hire a caregiver who provides care at the needed times. The Newmans (#3) felt that the control of the program gave them the ability to monitor their father's well-being. Mrs. Arroyo (#9) liked to control the quality of care her autistic daughter Marilena received. Kent Joyner (#10) said that controlling his care gave him something to do. Richard Trappani (#6) also liked keeping track of his care plan and expenditures. Mr. Beal (#16) and Mrs. Erdman (#5) liked the feeling of independence that control of the program gave them. Ms. Cannon (#23) felt that she was able to keep her dignity because she does not have to ask permission to buy every thing she needs.

Flexible use of the cash allowance was very important for Florida consumers (#4, 5, 11, 12, 13, 15, 17, 18, 22, 23, 24). Consumers (#4, 11, 12, 15, 17) can buy more supplies, more cheaply when they buy supplies themselves. Parents of children with disabilities use the money to pay for therapy not covered by Medicare.

The importance of choice (#4, 5, 6, 16, 24) in the program was related to control and flexibility. Consumers liked to choose their hours (#5). Richard Trappani (#6) received more help because he was able to choose his caregiving hours. Mrs. Jansen sums up the benefits of the CDC program by saying that it gave her "peace of mind."

Appendix A

Case Selection Criteria

Unit #	Age 18-64	65-79	80+	Male	Female	Black	White	Rural	Urban	F	PCW	N-F PCW	Rep	N-Rep
Unit #1		x			x		x		x			x		x
Unit #2	x				x		x	x			x			x
Unit #3			x	x		x			x		x		x	
Unit #4	x			x		x			x			x		x
Unit #5	x				x		x	x			x			x
Unit #6		x		x		x			x			x		x
Unit #7			x		x		x		x		x			x
Unit #8	x			x		x			x		x			x
Unit #9			x		x	x		x			x			x
Unit #10		x		x		x		x				x		x
Unit #11			x		x	x		x				x		x
Unit #12			x		x		x	x			x			x
Unit #13			x		x	x			x			x		x
Unit #14		x			x	x			x		x			x
Unit #15	x				x	x		x			x			x
Unit #16	x			x		x			x		x		x	
Unit #17		x		x			x	x				x	x	
Unit #18	x				x		x		x		x			x
Unit #19	x				x		x	x			x		x	
Unit #20	x			x			x	x			x			x
Unit #21	x			x		x			x		x		x	
Unit #22	x			x			x	x			x		x	
Unit #23		x			x		x		x		x			x
Unit #24			x	x		x			x		x		x	
Unit #25			x		x	x			x		x		x	
Unit #26		x			x	x			x		x			x
Unit #27	x			x			x		x		x		x	

Appendix B

Interview Protocols

CONSUMER/REPRESENTATIVE PROTOCOL

ENGLISH VERSION

**Cash and Counseling Ethnographic Study – AR
University of Maryland, Baltimore County**

Protocol # : _____

Interviewer: _____

Today's Date: _____

Consumer/Representative Protocol
Cash and Counseling Ethnographic Study – Arkansas

University of Maryland, Baltimore County

Introduction: Hello, my name is (interviewer's name). I am an interviewer for a study being conducted by the University of Maryland to learn first hand about your experience as a participant in the (official name of state's program). Rather than asking you a list of questions, I would like for us to have a conversation about how you came to be involved in the program and how it has worked for you.

I would like to tape record our conversation so that I can listen closely to what you are telling me. I want to remind you that everything you tell me will be confidential. If, after I leave, you have questions about the interview or our study you may call Dr. Kevin Eckert at the toll free number on this card.

I expect that our conversation will last about one hour. Do you have any questions?

1. Protocol #:

2. Date:

3. Interviewer:

4. Address:

5. Age:

6. Sex:

7. Marital Status:

8. Race/Ethnicity:

Protocol # _____
Date _____
Interviewer _____

BACKGROUND

9. Can you tell me about who lives with you?

9a. How are they related to you?

GENERAL PROGRAM

10. How did you hear about the program?

11. Why did you decide to become a participant in the program?

12. Can you tell me about the kinds of things you need help with? (P)

Protocol # _____
Date _____
Interviewer _____

13. How does participating in this program help you? (P)

SERVICE

14. Please tell me about your Personal Care Worker

14a. Did you know your care provider prior to hiring her/him?

14b. What is his/her relationship to you?

14c. What does he/she do for you?

14d. What is your PCW's weekly schedule?

14e. What tasks does your PCW perform for you?

14f How many hours per week does your PCW work for you?

Protocol # _____
Date _____
Interviewer _____

14g What are the pay arrangements?

14h. How many hours does your PCW get paid for?

14i. -Who manages and supervises your caregivers?

15. -What do you think are the most important services your caregiver provides you with?

16-do you feel your current arrangement is better than what you had before? (P)
(in regard to family or non-family caregivers)

17-What qualities do you look for in paid provider?

Protocol # _____

Date _____

Interviewer _____

CONSULTANT/REPRESENTATIVE

Please tell me about your Counselor

18. -What does he/she do for you? (P)

For consumers with representatives:

Please tell me about your Representative

19-What is the relationship of the representative to you?

19a. -What does he/she do for you?

19b. -What are the most important service he/she provides?

Protocol # _____

Date _____

Interviewer _____

19c. -Do you think it is better to have a family member or a non-family member as a representative?

OPERATION OF PROGRAM

20. What is the most important benefit you have received by participating in the IndependentChoices program?

21. What did you do before the program to address your needs?

22. What are the most important changes in your life since the program?

23. In addition to the help you receive from, what other sources of help have been most important to you? *e.g. church, volunteers, meals on wheels, etc.*

Protocol # _____

Date _____

Interviewer _____

24. What advice would you give to somebody else who might be interested in participating in this program?

25. -What do you think are the benefits of participating in the program?

26. -What do you think are the drawbacks of participating in this program?

FAMILY CAREGIVER PROTOCOL

ENGLISH VERSION

Cash and Counseling Ethnographic Study – AR
University of Maryland, Baltimore County

Protocol # : _____

Interviewer: _____

Today's Date: _____

Family Caregiver Protocol

Cash and Counseling Ethnographic Study – Arkansas

University of Maryland, Baltimore County

Introduction: Hello, my name is (interviewer's name). I am an interviewer for a study being conducted by the University of Maryland to learn first hand about your experience as a participant in the IndependentChoices program. Rather than asking you a list of questions, I would like for us to have a conversation about how you came to be involved in the program and how it has worked for you.

I would like to tape record our conversation so that I can listen closely to what you are telling me. I want to remind you that everything you are telling me will be confidential. If, after I leave, you have questions about the interview or our study you may call Dr. Kevin Eckert at the toll free number on this card.

I expect our conversation will last about one hour. Do you have any questions?

Date:

Interviewer:

Protocol #:

Place:

Caregiver Name:

Date of Birth:

Ethnicity:

Marital Status:

Highest Degree Obtained:

Relationship to Consumer:

Do you have another job?

- 11.a. If so, what is it?

Protocol # _____

Interviewer _____

Date _____

BACKGROUND

When did you begin *helping* your family member?

12a. *When did you begin providing paid services for your family member?*

12b. Who hired you and how were you hired?

What kind of training and experiences do you have to help you in providing services the client?

13a. -Do you have past experience as a PCW?

-Would you consider providing care to people outside of your family now or in the future?

SERVICE

-Do you live with your family member?

-What do you do for him/her?

How many hours a week do you work for your family member?

-What is your schedule like?

Protocol # _____

Interviewer _____

Date _____

What sort of tasks do you perform for your family member on a day-to-day basis?

Can you describe a typical day?

Do you get paid for all the care you provide?

How do you decide/Who decides what you need to do?

22a. -Does anyone supervise your work?

22b.-What kind of supervision do you get? (P)

Have there been any serious medical/non-medical problems that you haven't been able to handle on your own?

23a -What sort of help/advice did you get?

23b -Who gave you help/advice?

How would you describe your relationship with your family member?

Protocol # _____

Interviewer _____

Date _____

24a. -Have there been any differences or conflicts?

24b. -If so, what sort of conflicts have there been?

24c. -If any differences/conflicts have emerged over time, how have you resolved them?

Have your relationships with family members changed since *becoming a paid worker* involved with IndependentChoices? How?

Are there any particular concerns you have about your family member when you're not there?

-How have other members of the family/friends reacted to you and the services you provide to the family member?

OPERATIONS

Has your work, schedule, or the tasks you perform changed since you enrolled in IndependentChoices?

28a -If so, how?

Protocol # _____

Interviewer _____

Date _____

Since being a part of this program, have you needed added information or assistance in providing services?

29a.-please explain

What do you like most about working for (name)?

What is the hardest or most stressful part of the job?

What kind of skills or personality does it take to do this job?

32a. -Would you recommend this job to someone else?

32b. Why or why not?

Will you continue doing this work in the future?

33a. - *continue for family member*

other family member(s)

friends

unknown consumers

33b. Why or why not?

34. Based on your experience, how is being a personal care worker in the IndependentChoices program similar to or different from other work you may have done as a personal care worker?

Protocol # _____

Interviewer _____

Date _____

35. What's the best part of being a provider in the program?

What kinds of problems have you encountered in this program?

NON-FAMILY CAREGIVER PROTOCOL

**Cash and Counseling Ethnographic Study – AR
University of Maryland, Baltimore County**

Protocol # : _____

Interviewer: _____

Today's Date: _____

Non-Family Caregiver Protocol
Cash and Counseling Ethnographic Study – Arkansas

University of Maryland, Baltimore County

Introduction: Hello, my name is (interviewer's name). I am an interviewer for a study being conducted by the University of Maryland to learn first hand about your experience as a participant in the IndependentChoices program. Rather than asking you a list of questions, I would like for us to have a conversation about how you came to be involved in the program and how it has worked for you.

I would like to tape record our conversation so that I can listen closely to what you are telling me. I want to remind you that everything you are telling me will be confidential. If, after I leave, you have questions about the interview or our study you may call Dr. Kevin Eckert at the toll free number on this card.

I expect our conversation will last about one hour. Do you have any questions?

Date:

Interviewer:

Protocol #:

Place:

Caregiver Name:

Date of Birth:

Ethnicity:

Marital Status:

Highest Degree Obtained:

Relationship to Consumer:

Do you have another job?

- if so, what is it?

Protocol # _____

Interviewer _____

Date _____

BACKGROUND

When did you begin providing paid services for (client's name)? ***Did you know him/her prior to becoming his/her paid worker?*** Who hired you and how were you hired?

What kind of training and experiences do you have to help you in providing services to (name)?

-do you have past experience as a PCW? (P)

How many hours a week do you work for (name)?

-what is your schedule like?

-what do you do?

-do you live with (name)? (P)

Do you get paid for all the care you provide? (P)

SERVICE

What sort of tasks do you perform for (name) on a day-to-day basis?

Can you describe a typical day?

Protocol # _____

Interviewer _____

Date _____

How do you decide/Who decides what you need to do?

-does anyone supervise your work?

-what kind of supervision do you get? (P)

Have there been any serious medical/non-medical problems since you've been helping (name)?

-how did you handle that?

-what sort of help/advice did you get?

-who gave you help/advice?

Have you had any physical problems of your own since providing care for (name)?

How would you describe your relationship with (name)?

-have there been any differences or conflicts?

-if so, what sort of conflicts have there been?

-if any differences/conflicts have emerged over time, how have you resolved them?

What kind of contact/relationships do you have with (name's) family or friends?

Protocol # _____

Interviewer _____

Date _____

Are there any particular concerns you have about (name) when you're not here?

-how have members of (name's) family/friends reacted to you and the services you provide to (name)?

OPERATIONS

Has your work, schedule, or the tasks you perform changed since you became involved in the IndependentChoices Program?

-if so, how?

Since you became a part of this program, have you needed added information or assistance in providing services? (P)

-please explain

What do you like most about working for (name)?

What is the hardest or most stressful part of the job?

What kind of skills or personality does it take to do this job?

-would you recommend this job to someone else? Why or why not?

-Will you continue doing this work in the future? Why or why not?

Protocol # _____
Interviewer _____
Date _____

Based on your experience, how is being a personal care worker in the IndependentChoices program similar to or different from other work you may have done as a personal care worker?

What's the best part of being a provider in the IndependentChoices program? What kinds of problems have you encountered in this program?

COUNSELOR PROTOCOL

**Cash and Counseling Ethnographic Study – AR
University of Maryland, Baltimore County**

Protocol # : _____

Interviewer: _____

Today's Date: _____

Counselor Protocol

Cash and Counseling Ethnographic Study – Arkansas

University of Maryland, Baltimore County

Introduction: Hello, my name is (interviewer's name). I am an interviewer for a study being conducted by the University of Maryland to learn first hand about your experience as a participant in the IndependentChoices program. Rather than asking you a list of questions, I would like for us to have a conversation about how you came to be involved in the program and how it has worked for you.

I would like to tape record our conversation so that I can listen closely to what you are telling me. I want to remind you that everything you are telling me will be confidential. If, after I leave, you have questions about the interview or our study you may call Dr. Kevin Eckert at the toll free number on this card.

I expect our conversation will last about one hour. Do you have any questions?

Date:

Interviewer:

Protocol #:

Place:

Counselor Name:

Ethnicity:

Highest Degree Obtained:

Protocol # _____

Interviewer _____

Date _____

BACKGROUND

What is your current job title?

-length of time in position

-current caseload

-current IndependentChoices caseload

What percent of you clients have family members as providers?

How many of your IndependentChoices clients are severely disabled? (P)

GENERAL

How did you become involved with this IndependentChoices client?

How many hours a *month* do you devote to working with this client?

-how many contacts do you have a *month*?

-how are the contacts made? (telephone, face-to-face, etc)

-who initiates the contact?

What do you do for the client?

Have there been any start-up problems for your client?

Protocol # _____

Interviewer _____

Date _____

-how did you resolve these/who did you work with to resolve problems?

SERVICE

How do you work with the client and the PCW's?

What kinds of training and advice have you provided to the client? What kind of assistance do you provide?

Is (client's name) getting the services provided in this cash plan?

What do you look for as a counselor monitoring an IndependentChoices client?

For (client's name) have you done any of these things?

OPERATIONS

Have there been any problems that have arisen *since becoming a counselor* in the IndependentChoices program?

-if so, what have they been?

Have there been any problems working as a counselor with (client's name)?

How are your counseling responsibilities *for (name)* different than for *people you assisted in the past*?

Based on your experience, what factors affect your client's ability to supervise his/her own care?

Protocol # _____

Interviewer _____

Date _____

- i.e.—hiring, firing, supervising, for example

- are characteristics such as age, sex, or previous employment important in directing care for themselves?

In your experience, does the quality of care differ between family and non-family providers?

-what do you think is the biggest difference between family and non-family providers?

- do you think there are differences in the quality of care depending on the type of family relationship (i.e.—daughter, daughter-in-law, husband, son, etc.)?

-what are the primary strengths and weaknesses of *different* kinds of care?

-family vs. friends

- known vs. unknown

- family vs. agency

Given your experience, what do you think the benefits are in the IndependentChoices program?

-what are the problems?

-what changes would you suggest to improve the program?