

# **CASH AND COUNSELING DEMONSTRATION AND EVALUATION**

## **Report on Florida Paid Worker Focus Groups**

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## FORWARD

To operate a successful consumer-directed program, consumers must be able to choose from an adequate supply of qualified workers. Yet the supply of direct care workers has been limited throughout the country, including the Cash and Counseling Demonstration states. Traditional agencies also have been limited in their ability to serve consumers due to this worker shortage.

To help address this growing problem, and learn more about these workers, we conducted focus groups with paid workers of clients enrolled in the Arkansas and New Jersey Cash and Counseling Demonstration and Evaluation (CCDE). Focus group participants were workers for elderly clients or adults with physical disabilities. Given that Florida is the only one of the CCDE states to enroll children under 18 with developmental disabilities, we decided to conduct groups with paid caregivers for this population to learn if there might be unique issues for them. As with the groups conducted in Arkansas and New Jersey, we wanted to learn workers' views about issues such as job satisfaction, roles and responsibilities, and ideas for recruiting and retaining new personal care workers. We also wanted to learn similarities and differences between paid family caregivers and non-family caregivers.

These discussion groups provided rich data about the experiences of paid workers who care for children with developmental disabilities in Florida's CCDE program, Consumer Directed Care (CDC). We learned about similarities between paid family and non-family workers, such as the strong dedication both groups felt toward their caregiving job. Both groups also expressed the need for health benefits. Focus group participants had creative ideas for recruiting and retaining new workers, such as recruiting college students enrolled in special education degree programs. They responded positively to the idea of a central "registry" that could link workers and consumers needing personal care services.

The Robert Wood Johnson Foundation provided funding for the focus groups.

### **Introduction and Methodology**

In April 2004, two focus groups were conducted in Tampa, FL with paid caregivers of children under age 18 with developmental

disabilities. The Department of Family Services mailed letters of invitation to parents of children enrolled in Consumer Directed Care inviting their child's primary paid worker to attend one of two focus groups. (See Appendix A) If the parent was not the primary paid worker, they were encouraged to have the primary worker respond to the invitation. Those interested in participating in the focus groups were asked to call the focus group project manager who further screened each caller in order to assign them to the appropriate group.

## **Demographics**

Ten CDC paid workers participated in the two groups. Four of the caregivers were related to the child for whom they provide care – 3 mothers and 1 grandmother. The other six were non-family members. Three of the non-family workers knew the children before becoming paid caregivers. Following is a brief overview of each participant, their relationship to the child for whom they are a caregiver, and the number of paid hours worked.

- Female, age 72: cares for 11 year-old grandson who is autistic and has slight mental retardation. She is paid for 20 hours a week.
- Female, age 24: cares for 11 year-old girl with cerebral palsy. They are not related. She works 30 paid hours a week.
- Female, age 45: cares for a 12 year-old girl with severe cerebral palsy. They are not related. She works 25-30 paid hours weekly.
- Female, age 50: cares for her 20 year-old daughter who has severe cerebral palsy and mental retardation. She is paid for approximately 26 hours weekly.
- Male, age 30: cares for a 15 year-old boy who has Down's Syndrome. They are not related. He works 40 hours weekly.
- Female: age 42: cares for a 9 year-old boy with autism. They are not related. She works between 50-60 hours monthly.
- Female, age 49: cares for two siblings a boy, age 8 and a girl, age 9. Both who have spina bifida. The caregiver is not related

to the children. She is paid for up to 40 hours a week for both children.

- Female, age 38: cares for her 11 year-old daughter who has Rhett Syndrome, involving severe cognitive and physical disabilities that require help with all activities of daily living. She is paid for 40 hours weekly.
- Female, age 42: cares for her 16 year old daughter who has agenesis of the corpus callosum, similar to cerebral palsy. She is paid 21 hours weekly.
- Female, age 60: cares for a 13 year old boy who is autistic. They are not related. She is paid for 20 hours a week.

### **Focus Group Issues and Themes**

The issues covered in the Consumer Directed Care paid worker focus groups centered on the following topics:

- Becoming a Personal Care Worker
- The Transition from Unpaid to Paid Caregiver
- Overview of Roles and Responsibilities
- Being A Personal Care Worker
- Differences between Family and Non-Family Caregivers
- Linking Workers and Consumers

**Statement of Limitations:** Focus groups afford the opportunity to observe and record spontaneous reactions – perceptions, opinions, and attitudes – from a selected group of participants on a variety of issues and topics. The groups help develop insight and direction rather than quantitatively precise or absolute measures. It should be noted that the participants in the focus groups were “self-selected”. As is the case with any group of self-selected participants, they may or may not be typical of the selected populations for these groups in Florida – Consumer Directed Care workers.

Statements in the report noted in *Italics* are actual quotes taken from the focus group transcripts. In some cases, the sentence structure may seem awkward – a result of the spoken word seen in writing. When appropriate, the speaker of the quote will be noted in parenthesis.

## **Becoming a Paid Worker**

### ***Non-Family Paid Workers***

Of the six non-family paid workers, three knew the children they care for through their church. One had cared previously for another child with a developmental disability and met the current family she works for through a neighbor. Another worker first started working with a child when she was a personal care assistant at a home health agency. She left the agency and was then hired by the family to care for their child. Another worker was a teacher at the child's school and was asked by the family to be his primary paid caregiver.

### ***Family Paid Workers***

One woman had been caring for her autistic grandson since he was four years old. Her daughter-in-law asked if she would consider being her grandson's paid worker should they be accepted into Consumer Directed Care.

Two of the three mothers became their child's primary paid worker because they had difficulty finding reliable workers when they were working full time (one as a Support Coordinator for Department of Family Services). Each has children who are severely handicapped and need constant attention. As a result of becoming the primary paid worker, these two moms were able to quit full-time work. Both now assist their husbands with their businesses on a part-time basis.

*For me it's probably the best thing that happened to us. I love it. Why is that? Because we've had a lot of bad experiences with health care providers, nursing. Now I can stay home with her and it helps make up for not having my job. (Mother)*

*I feel the same way. Now I'm not limited to who is in contact with my daughter. Last year, my son was 19 and he was one of the paid caregivers, and my other daughter. So her siblings were with her a lot and you could tell the difference in her having someone she's familiar with working with her as opposed to a stranger. We went through a lot of people. Now there is more stability. (Mother)*

Whether a family member or not, all of these paid workers saw their work as a labor of love as opposed to just a job, or even a profession.

*I would say it's a labor of love. It's something I'm doing while I'm going to school. (Non-family)*

*For me, it's absolutely a labor of love. Although, if I were ever to move, this is a profession that I could see somewhere else. (Non-family)*

*I love him to death. I've taken care of him since he was 4. It's nice to be paid for it. (Family)*

## **Overview of Roles and Responsibilities**

The paid workers who are mothers assume most all caregiving tasks for their children, all of whom are severely disabled and need total care.

For the non-family caregivers, there is a wide range of tasks that they do for the children.

- The male caregiver for a 15-year old boy with Down's Syndrome cares for him on weekends. Activities range from attending sports events together to helping the child learn to perform certain tasks, such as tying his shoes.
- One caregiver, a behavioral specialist, works with a child to improve behavior, manners and social skills.
- Several workers perform personal care activities or work with the children to help them learn to do the tasks by themselves.
- Helping with school work, doing special exercises, and taking children to girl scouts or dance classes are among other activities these paid caregivers do with the children.

Several of the non-family paid workers have letters of agreement with the child's parents. Others have detailed schedules specifying what needs to be done with the child. Parents provided any training needed to help care for their child.

Workers who have been with a child for several years commented on how their roles often change as the child grows older. For instance, they may move from performing certain activities for a child, such as bathing and dressing, to teaching the child to do these activities for themselves.

*As I've been there things have changed. Before I would bathe her, make her meal, get her ready for bed and do all the evening type stuff. As she's gotten older we realize that it's time for her to start doing these things for*

herself. So my job switched from doing them all for her to walking her through doing them herself. It has evolved. (Non-family worker)

## **The Best and Worst of Being a Personal Caregiver**

### ***The Best Part***

Family and non-family paid workers alike spoke of a special relationship they have with the child for whom they provide care. They spoke of “making a difference” or teaching a child something. For parents, Consumer Directed Care has enabled them to be at home and have more control over their child’s needs.

*My relationship with Haley. She’s like my little sister. I’m an only child and so is she. They’ve become family and they treat me like family. They’ve taught me a lot about children with special needs. Since I’m going into that field, it’s been an eye opening experience. I’ve gained a lot of knowledge. (Non-family Member)*

*The best part is that I’m helping my daughter to try and make her life easier. Just the little bit of money I get helps me do something out of the house. We can go out of town for a weekend. Support that I can count on from the program. (Family member)*

*The best part is to see that it’s making a difference in his life. To see something that I taught him or hear a phrase that I taught him (Non-family Paid Worker)*

*Just being there with her and know that she’s getting what she needs. She knows that whoever is with her loves her. When I hold her and she looks at me like I’m the best thing that ever happened to her. (Family Paid Worker)*

*I think the best part is having a voice and being able to control a lot of things that happen with Jewell. Not having to leave her home and still be able to contribute to the family income. (Family Member)*

*Probably the best part is seeing that I have taught Vinnie something. That I did completely potty train him by myself. (Non-family Paid Worker)*

### ***The Worst Part***

For several of these paid caregivers it was difficult for them to think of the worst part of the job. If anything, they preferred to look at this in terms of a hard or difficult aspect of caregiving. Several of the non-family paid workers said that at times it was difficult dealing with the child’s parents.

*The hard part is the parents. I never want to do anything to offend them. They are so over protective and sometimes I know they need to ease up. But I'm not that parent, so I have to respect them. (Non-family Paid Worker)*

*The worst part is Mom kind of lets him get away with more than he should. I have a little bit of discipline in there and I'll say "sit and eat" and he wants to watch TV. Mom will say "just let him go". "No, he needs to eat now". (Non-family Paid Worker)*

*The power games. If I say no, Haley will say "I'll just ask my mom". But that's normal pre-teen stuff. Just dealing with a pre-teen. I don't have much to complain about. The job is wonderful. (Non-family Paid Worker)*

Certain aspects of providing care for a child can be difficult for some.

*The hard part is the repetitive tasks every day. It's constant. If you don't want to get up at 5:30, you have to anyways and start tube feeding and bowel care. (Mother)*

*The worst part is when he gets combative and I realize he's getting stronger. I've had to figure out a way to get there before he does. When they are mad they are strong. I understand why he gets mad, it's got to be tough not being able to tell someone what's the matter. (Grandmother)*

## **Respect**

These paid workers had no doubt they were respected by the children's parents.

*Judy always says "what Sean says is law". So I feel like they will back me up. They don't undermine what I say. (Non-family Paid Worker)*

*Michelle is very appreciative. She's there to watch me, so she knows I'm doing as she would like. Because it is her home. (Non-family Paid Worker)*

*Yes. They tell me quite often that they couldn't be without me. (Grandmother)*

## **Family vs. Non-Family Caregivers**

Non-family caregivers felt that they could often take a different approach with a child than parents could. While sometimes it is easier and less time-consuming for parents to do things for their children, a paid worker can spend more time on certain tasks with the child.

*That there are certain things that when it's my time with her, she knows she won't get away with saying no. Dressing, brushing her teeth. She*

*can put up a fight with Mom and Mom is likely to give in and dress her and give her a bath to get it done. Whereas, it's my time with her and my job is to do those specific jobs. If it takes us two hours to take her bath that's less time to do fun stuff. So it's helped their family that I'm not Mom or Dad. I'm Sean, big sis. And I can get her to do a lot more than Mom and Dad can. They appreciate that and are aware of that. (Non-family Paid Worker)*

*Non-family members tend to be more objective. Which is probably a good thing most of the time. (Non-family Paid Worker)*

*I think we are more into teaching. (Non-family Paid Worker)*

*– I would think that maybe the ones that are not connected to him will make him do things that I won't make him do. I do the essential things, but in a loving way. I get around it. Sam (the aid) can come in and say "do this" and he does it (Grandmother)*

*Mom and Dad think of survival – these are my kids, I have to take care of them and make sure all of their needs have been met. When you are not in that all day, every day, you can focus on specializing in certain areas that parents can't do. (Non-family Paid Worker)*

*We are trying to make them more independent, where the parents will just do it for them. (Non-family Paid Worker)*

*Vinnie's mom still dresses him and he's 13 years old. I showed her one day that he can dress himself. She couldn't believe it. (Non-family Paid Worker)*

*I think they [parents] are more like "just do it and get it done", whereas I can take the time and talk them through it. She doesn't have the time. (Non-family Paid Worker)*

*If he's looking forward to doing something I'll say "no, I heard you weren't listening to your mother. If you listen and do what you are supposed to do, you'll be rewarded. If not, you won't do anything". And it works. He respects his mother more than he did before. She let him run over her a little. A lot of that has stopped. (Non-family Paid Worker)*

## **Effects on Personal Life**

Several of the non-family paid workers reported that they work many more hours than those for which they are paid. But they do not see this as a burden because the child they care for has become an integral part of their lives. One caregiver stated she felt that she sometimes led two separate lives – one as a caregiver and one as a college student. But she feels neither gets shortchanged.

When asked about health concerns, participants often cited back problems. This problem developed as children got bigger and heavier, making it more difficult to move them.

Family members who are paid caregivers were asked if they find that being the paid worker was more or less stressful for them than being an unpaid caregiver. They all overwhelmingly stated it was far less stressful for them.

*Less stressful. Why? I don't know who determines the hours, but when we get more money we have bought equipment. I know I will be paid some money I can count on. (Mother)*

*Less stressful for the whole family. Mainly because they feel that they can call on me without imposing. (Grandmother)*

*It took the financial burden off the whole situation and trying to find someone to help you so you can go to work. It's like I have a job now, in the home. Just like cleaning the house. It's less stressful to do that than to worry about who is taking care of the kids. (Mother)*

Non-family workers as well as the grandmother who cares for her grandson spoke of how they believe their presence makes a positive difference for the families for whom they work.

*It's freed his mom when we are all in the house together. She can spend time with Daniel, go outside or whatever. It's a benefit for Michelle to have that extra time with her son when she can. (Non-family Paid Worker)*

*It's freed them up to have normal family time. Like they'll take the two and go to Disney for the day and have a normal family life. (Grandmother)*

*I think it's less stressful. They get to go out and do things. The mom gets to take the sister to Orlando or whatever, where she couldn't take Vinnie. (Non-family Paid Worker)*

*I think it's less stressful. The mother wants to work and her husband doesn't want her to. So if I can just give her 3 hours to get out and feel a little independent. She's really happy with it. It seems to be good for the family. (Non-family Paid Worker)*

Another non-family worker explained that she is probably earning as much money as she could, given her situation.

*It's working well for me right now. Are there other jobs where you would make more? I don't think so because I've been out of the work force for 20 plus years. I could not step into something that would pay better than*

*this. So you feel that you are getting what you need? Right. Non-family Paid Worker)*

## **Linking Workers and Consumers**

Focus group participants were asked to share their ideas about ways to connect workers with clients who need a worker. One participant suggested that the programs that oversee home care services could keep a worker data base.

*Maybe if there was some sort of way to get in touch with the actual program and register people who are looking for jobs. I have networked with people who are interested in being personal care givers and I know of families who need them. (Non-family Paid Worker)*

Another participant suggested contacting other in-home care providers.

*When I got the letter, since I am a home-care provider, there are a lot of providers that work just with disabled children, so I sent the letter to all of them and told them to call you. (Non-family Paid Worker)*

Participants responded positively to the idea of a registry and several said they would consider participating in one. They had no problems or concern with the idea of a background check.

## **Observations and Conclusions**

As has been noted with paid workers in other CCDE states, these Florida paid workers expressed satisfaction and a great sense of fulfillment in their roles as paid caregivers.

Unlike paid workers in other states, these workers did not express strong feelings of isolation. These workers interact extensively with the child's family, which may prevent such feelings of isolation.

Paid workers for children with disabilities under the age of 18 felt as if they have two clients – the child for whom they provide care and the child's parents. This can be challenging, but they also believe that a strong relationship with parents results in feeling respected and less isolated.

For the non-family paid workers, the scope of work tends to be very defined – more so than the roles and responsibilities of paid workers for elders. The scope of work can change over time as a child grows older.

The focus group participants liked the idea of a registry to link workers and consumers. They had no problem with background checks.

Several of the non-family workers stated they would strongly consider being a paid worker for other children.

## Appendix

## Cash & Counseling

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Project Director: Kevin J. Mahoney, Ph.D.  
Research **Director**: Lori Simon-Rusinowitz, Ph.D.  
Deputy Project Director, Kristin Simone, M.M.

University of Maryland Center on Aging

Date

Name  
Street  
City

Dear

We are writing to tell you about a **focus group discussion taking place later this month for paid caregivers participating in Florida's Consumer Directed Care Program**. Consumer Directed Care is part of a national research project called Cash & Counseling.

As you know, XXXX, was selected to participate in Consumer Directed Care, which allows you to arrange and manage his/her own personal care services. You or your child's paid caregiver may have participated in a telephone survey that asked you questions about the experience of being a paid caregiver in Consumer Directed Care. This discussion group is being held along with the telephone survey, and will help us learn more from paid caregivers participating in Consumer Directed Care. Some of the topics we would like to discuss include: Why did one decide to become a paid caregiver? What are the best parts of one's job as a caregiver? What is the most difficult? Is it easier or harder if the caregiver is related to the person for whom they are providing services?

The focus groups are for your child's **primary paid caregiver**. If you are not the primary paid caregiver, we ask that you share this letter with that person and encourage him/her to consider participating in the group discussion. The groups will take place on **Tuesday, April 27 at 4 and 6 pm. in Tampa**. The group will consist of 8-10 other people who are also personal caregivers. Food will be served and \$50.00 will be given to participants in appreciation for their time and effort.

Please note that participation in the discussion group will be strictly confidential. Our report will not include any names of caregivers.

If your child's primary caregiver is interested in attending one of the groups, please contact Ms. Lee Zacharias, the focus group manager, at **1-800-589-3583 no later than Tuesday April 20, 2004**. Ms. Zacharias can answer any questions you may have and can provide more information about the groups. We look forward to hearing from you.

Sincerely,



Kevin J. Mahoney, PhD  
National Project Director



Lori Simon-Rusinowitz, PhD  
Research Director

CASH & COUNSELING DEMONSTRATION & EVALUATION  
**FLORIDA CONSUMER DIRECTED CARE**  
**PAID WORKER FOCUS GROUPS**  
ISSUES GUIDE

**Introductions/Warm-up**

- Please introduce yourself and briefly tell us about the person for whom you are a personal caregiver.
- What you think of Consumer Directed Care?
- What do you see as the advantages/disadvantages of a consumer-direction cash option?

**On Becoming a Personal Care Worker**

- Have you been a personal care worker before? In an agency? Private setting?
- How did you get your current job?
  - What is your relationship to the client?
  - *Were you already doing tasks as an unpaid worker?*
  - *If so, what made you decide to become a paid worker?*
  - *What were your reasons for accepting a position as a paid worker?*
    - *Did you want to become a paid worker for your relative?*
    - *Was it your choice?*
    - Did the client's family approach you or did some one else recruit you?
  - How long have you been a paid worker for this person?
- *Do you have other jobs besides being a personal worker?*
- Do you see yourselves as “professionals” or is this a “labor of love”?

## Overview of Roles and Responsibilities

- Tell us about your work. How was it decided what your responsibilities would be?
- For those of you already handling tasks, have things changed...how have things evolved?
- Did you and your client's family design a "letter of agreement" describing expectations and responsibilities?
- Do you and your client's family routinely monitor and assess the caregiving situation?
- For those of you who are caring for family members, are other members of your family involved in the client-worker relationship? Is so, please describe. How about those of you caring for a non-family member?
- *Does your client have a representative? If so how does the consumer-representative relationship work?*
- Training Issues:
  - Who trained you for the tasks you are doing?
  - Do you think you were adequately trained?
  - Is there anything that could have improved the training?
- What is your schedule?
  - [Probe: Do family members work more hours than non-family members? Do they tend to work more weekends, nights?]
  - For family members: are you adding paid family care to other work you are doing? Were you able to decrease your hours in your other job?
  - Are you able to be flexible in your work schedule? What factors affect your work schedule?
  - Do you and your client have a back-up plan if you are unable to work? Have you had to implement that plan and if so, did it work?
- If you had a problem as a paid worker, where would you go, whom would you turn to for advice?

## ***On Being a Personal Care Worker***

- What is the best part of being a personal caregiver? The worst?
- When I meet with other health care employees, they talk a lot about “respect”...about wanting to be respected by those for whom they work...
  - What does “**RESPECT**” mean to you? Can you describe it?
  - Do you think your client respects you?
- Relationship of worker to the consumer: Do you think there is a difference if a worker is a family member or friend rather than some one unknown to the client?
- *Has being a personal caregiver affected **your privacy, your social life**?*
  - If so, in what ways? (Probe for differences between those workers living with the client and those who don't; those who are related or not).
- How is your **health**? Has your health changed since becoming a personal care worker? If so, how?
  - Are any of you experiencing new health problems?
  - Do you have chronic health problems that you feel have changed since becoming a personal caregiver? If so, how?
  - Do these problems interfere with your caregiving responsibilities?
- *Are there **stresses/strains** you're experiencing as a result of being a personal caregiver? (financial, personal, etc.)*

## ***Linking Workers and Consumers***

- What suggestions do you have to better link consumers and workers when a consumer does not have a friend or relative available to hire?
- Recruiting and retaining workers
  - Do you think an automated registry would be a useful way for consumers, workers and agencies to link workers and consumer? (By automated, we mean a registry in which workers would enter personal information, their professional qualifications and background check information. A consumer could enter personal information and personal caregiving needs.)
  - Would you participate in such a registry?

- Would you provide professional information about yourself for the Registry?
- Would you undergo a background check, including reference check and criminal background check?
- Would you pay a small fee (\$15 or so) to participate?
- What do you think the benefit of this registry would be?
- What do you think the image of in-home workers is among the general population?
- Do you think the image of in-home workers needs to be changed? If so, how?

### **Closing**

- Would you consider another position as a personal care worker or something similar?
- For family members who became paid workers: Would you consider being a paid worker for a non-relative when your family member no longer needs your help?*
- What would make this a better job...one where more people would want to stay?
- Any final comments?
- Thank you for your participation.