

CASH AND COUNSELING DEMONSTRATION AND EVALUATION

Report on New Jersey Paid Worker Focus Groups

Submitted by: B. Lee Zacharias

June 2004

**Supported by
The Robert Wood Johnson Foundation**

Submitted to:

Kevin Mahoney, Ph.D.
Project Director
Cash and Counseling Demonstration and Evaluation
National Program Office
Boston College

Lori Simon-Rusinowitz, Ph.D.
Research Director
Cash and Counseling Demonstration and Evaluation
University of Maryland Center on Aging

Table of Contents

<u>Section</u>	<u>Page</u>
Forward	3
Introduction and Methodology	4
Demographics	5
Focus Group Issues and Themes	6
Overall Impressions of Personal Preference	7
Becoming a Personal Care Worker	7
Moving from Being an Unpaid to a Paid Caregiver	8
Overview of Roles and Responsibilities	9
On Being a Personal Care Worker	10
The Best Part	10
The Worst Part	11
Respect	11
Health	12
Family vs. Non-family Caregivers	12
Support	13
On Linking Workers and Consumers	13
Observations and Conclusions	14
<u>Appendix</u>	
Letter of Invitation	17
Issues Guide	18

FORWARD

To operate a successful consumer-directed program, consumers must have access to an adequate supply of qualified workers from which to choose. 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 New Jersey's Cash and Counseling Demonstration and Evaluation (CCDE), Personal Preference. 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 Personal Preference paid workers who care for family members. 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, more hours of service, feelings of isolation, and the desire for peer support. Focus group participants had creative ideas for recruiting and retaining new workers, such as recruiting individuals with disabilities who could perform certain caregiving duties. 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

Projections of increased demand for services needed by a growing population of elderly, aging baby boomers, and increased interest in consumer-directed services provide an imperative to learn as much as possible about attracting and retaining good direct care workers. A critical component of understanding key workforce issues is to understand the perspectives of the workers themselves.

In May 2003, two focus groups were conducted in Secaucus. Letters of invitation (See Appendix 1) were sent to Personal Preference clients asking them to encourage their primary paid worker to participate in the groups. Interested workers then contacted the focus group project manager who further screened interested participants and assigned them to the appropriate group.

Funding was also available to conduct two focus groups with personal care workers from home health agencies. We worked closely with the director of one of the larger home care agencies who worked tirelessly to help facilitate groups with her workers. However, after three separate attempts we were unable to recruit enough participants to conduct the groups. Agency management felt that the location of the research facility (Secaucus) might not have been convenient for agency workers, even though we offered participants reimbursement for transportation costs.

Groups were then rescheduled in mid-June at a hotel in Newark located where there was good access to public transportation. Again we received no response to the invitation. However, at this point, location of the groups may have been less of a factor in the poor response rate than the political climate surrounding New Jersey's home health industry.

In late spring, legislation creating a Public Authority to govern all home health care had been introduced in the New Jersey legislature. According to Personal Preference staff, the issue created tension between the private home health agencies and the union representing health workers. Several agency directors said that some of the agency's home health aides were being strongly pressured by union members to support the establishment of a Public Authority and many were upset that they might lose their agency jobs.

Understandably, this atmosphere created a certain degree of mistrust towards “outsiders” coming in to conduct focus groups around the topic of jobs and job satisfaction.

We made a third and final attempt to conduct groups in early October, this time at a location within walking distance from one of the agencies. Despite assurances from the agency director that the groups had nothing to do with the issue of the Public Authority, uncertainty and skepticism were still strong among the workers. While about eight workers initially responded to the third letter of invitation, several later said they could not attend. At this point we decided to cancel the groups. After, further conversations with the agency director and the Director of the Personal Preference Program, we concluded that the current political climate precluded conducting groups with the agency workers in time for this study.

Group Demographics

The table below describes the composition of the groups. There were no distinctions between the two groups, so demographic information is combined. A more detailed description of the participants follows.

Group Description	Date & Location	Number of Participants
Paid Workers-family	May 2003	6
Paid Workers-nonfamily	May 2003	5

Overview of Personal Preference Paid Workers

- The age range for the Personal Preference paid workers was 20 to 57.
- Three of the six paid workers who were family members lived with the client. One of the non-family paid workers lived with the client.
- Many of the family members who were providing care had been doing so for many years.
- All but one participant was female.
- Following are examples of the clients who were receiving services from these caregivers:
 - An 83 year-old woman cared for by her live-in daughter

- A 62 year-old woman with heart disease and diabetes cared for by her granddaughter who lives with her.
- A 30 year-old woman who provides services to a 40 year old woman with Crohn's Disease and multiple psychiatric problems. They are not related.
- A 48 year-old woman who cares for her godchild, age 20 who has severe sickle cell anemia.

Focus Group Issues and Themes

The issues covered in the Personal Preference paid worker focus groups centered on the following topics:

- Becoming a Personal Care Worker
- Moving From Being an Unpaid to Being a Paid Caregiver
- Overview of Roles and Responsibilities
- Being A Personal Care Worker
- 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 New Jersey – Personal Preference paid 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.

Overall Impressions of Personal Preference

The Personal Preference paid workers had positive feelings about the program and the positive changes it brought to those enrolled in the program. Several stated their family member felt more comfortable being cared for by someone they know and trust.

I know that a lot of times the patient isn't always comfortable with who the agency sends out for them and I think it's an extra convenience to them, a comfort, when they can have someone that is close to them who they trust...

My mother feels more comfortable with my sisters and with me...

Focus group participants reported that Personal Preference has given their clients better care by giving them more control over their personal care and more independence.

I think she is more relaxed.

Personal Preference...is helping her explore her own independence.

She is more at peace now because she gets to pick whomever she wants.

Becoming A Personal Care Worker

Several focus group participants had performed personal care in other settings, such as a home health agency or nursing home before their current position as a paid worker in the Personal Preference program. In most cases, family workers were asked by their family member to care for them.

This program is a permanent job, my mother asked me to stay with her.

Non-family workers found their positions through friendships or job postings. According to several of these workers, some clients felt

better having a non-family member care for them because of complicated family dynamics.

...she had both of her sisters and I guess because her family bickered, they knew each others' ways so it was better for her not to have a family member.

Few focus group participants view their caregiving work as “just a job.” Family workers mentioned feeling committed to caring for their parents out of love and respect.

I had a choice. I could've gotten somebody else to do it, but I wanted to do it because it was my mother.”

I love this job. This is compassion and love. You work for your mother... for me, it's more than that.

Non-family workers also expressed strong commitment and viewed their personal care work as more than “just a job.”

To me it's more than just a job. At first, when I was first asked about it, it was a job because I was out of work and I needed the work, but as I began to get into the job...it just became a part of me.”

Moving From Being an Unpaid to Being a Paid Caregiver

Family workers reported that other family members were appreciative of their role as a paid caregiver.

My sisters are happy because I don't have any other job.

None of the caregivers felt that their relationship with the person for whom they were caring had changed since becoming the paid caregiver. They were asked if they felt differently since becoming the paid caregiver. For the most part, none reported feeling differently. Some mentioned minor changes in the social dynamics.

Sometimes I feel she can be bossy, my mother. She knows she's my boss and she says certain things that irritate me and I just ignore her, but that's my mom.

Some days we butt heads because it becomes friendship and job, it gets twisted.

All seem to derive satisfaction from their roles as paid caregiver.

I know my mom is satisfied. She is comfortable with me taking care of her and she feels comfortable bossing me around. I'm closer to her now...I'm more satisfied doing this.

I actually like helping people... that is my passion.

Overview of Roles and Responsibilities

For some, caregiving tasks and responsibilities seemed to evolve with the job.

You don't think of it, you just do it naturally.

It was mostly things that I knew she couldn't do herself, cook, bathe, washing clothes...I knew she couldn't do that so I just did it.

Others plan daily tasks with their clients.

We sat down together and we came up with a list and it's a list that we have posted.

Everyday I go in there. I more or less emphasize the fact that it's all about you, what do you want to do, what would you like to do today, would you like to go somewhere. She's the boss and she likes that. We didn't have any written plan, she just said she needed help and there were things she would ask me to do.

Some felt that expectations of them have changed, as if caregivers are now held more accountable given that they are being paid.

She says, 'now you won't get paid' (when I forgot to do something).

Others felt a sense of financial relief to get paid for work they were already doing anyway.

It felt like a little bit of a relief because...it's very hard financially, I laugh and say in all the ways I've taken care of you, you're taking care of me because now I can stay home and work.

Family and non-family workers all agreed that they provide more care than what they are paid to do, whether they live with the client or not.

Sometimes when she asks me to stay extra time I don't mind because she's my friend.

On Being A Personal Care Worker

The Best Part

Paid workers, family and non-family, reported that caring for someone, seeing them improve in health and independence, and feeling needed are the best parts of being personal care workers.

The best part is being able to take care of my mother. She's my best friend.

The best part is I've seen her health improve, I've seen her strength grow.

The most positive thing is seeing the client I work for become more independent.

The best part is knowing that I can get up in the morning and go because I know Lois is going to need me. That's a good feeling to be needed.

The best is that I'm there when my grandmother needs me.

The Worst Part

Personal care workers reported the worst aspects of their jobs as caregivers are lack of benefits and needing more hours for their caregiving.

The worst part is no benefits.

Focus group participants also reported that clients can be demanding.

The worst thing is she gets demanding. My god, she drives me nuts.

I don't have a life. My life is my mother seven days a week.

I feel tied down. I cannot go out.

Paid care workers reported that feeling isolated is another difficult aspect of their job.

The worst thing is feeling alone, carrying the responsibility alone.

Respect

Although one participant reported that she does not feel that the client respects her, most other participants felt they are respected by their clients and family members.

I feel she respects me; she talks to me and she shares. She asks my opinion; she tells me things I don't believe she would just tell anybody, little secrets, talk about the family.

She loves me the same way I love her so she has treated me the same all my life.

Health

Many of the caregivers reported that they have their own chronic health conditions. They reported that their own health problems have not changed as a result of their caregiving positions. Several said they are not as stressed as they were before they began the caregiving work.

I feel really better now because I used to be stressed and depressed sometimes.

The paid worker position provided more flexibility than previous jobs for some workers and enabled the family workers to have some respite. Participants saw positive changes.

I can now have more flexibility... I can actually go out, and that would be good for me.

Night time is really flexible; I can go out one or two days a week.

Family vs. Non-Family Caregivers

Focus group participants expressed some thoughts on differences between family and non-family caregivers. Those who were caring for a family member thought there were things they could do that non-family caregivers could not.

There are personal things we can do as a family member that others can't.

I didn't want someone looking at my daughter or touching my daughter...that is my child, my daughter.

They also thought it would be different for them if they cared for a non-family member. Some said they were not sure if they would feel comfortable. However, it is important to note that several said they would consider being a caregiver for someone else who was not a family member.

I would do it for other special children, elderly...when you see that child or that elderly person you forget that you are being paid.

Would you consider being a personal care worker for somebody other than a family member? In a heartbeat.

By far, there were far more similarities between family and nonfamily paid workers....mutual dedication, seeing the job as a “labor of love”, and a willingness to provide care beyond the hours for which they were paid.

Support

Focus group participants reported that they go to their family for help and advice. Many mentioned relying on God for support. They did not feel that Personal Preference consultants were available for support, due to high staff turnover.

Every time I turn around we've got a new consultant.

We've had the same one for two years and she never shows up. A telephone call don't do it.

On Linking Workers and Consumers

Focus group participants were asked for ideas on how to link workers with consumers. Participants listed places where one might recruit others to the caregiving profession: doctors' offices, developmental centers, Salvation Army, churches, unemployment agencies, supermarkets, schools, education departments at local community colleges were among those listed...

They all liked the idea of a registry that linked consumers and potential workers.

Participants offered the innovative idea of hiring others who have disabilities and could do some caregiving activities.

I mentioned my brother is disabled. He could help with certain people; he has a great personality.

The house I'm in, they're all adults. They all have to have jobs and they're all in the community and they have huge hearts. They would do anything for anybody and they're always asking me how can we do what you do. One of the residents signed up for the ARC companion program and she went through all the training we had to.

Observations and Conclusions

Personal Preference paid workers had positive feelings about being care providers. Both family and non-family caregivers felt dedicated to the individuals for whom they provided care. Several common themes about their work as personal caregivers emerged.

- Personal Preference workers believed that the individuals they care for get better care and feel more comfortable receiving care from someone they know.
- Family and non-family workers shared many of the same perspectives on feeling dedicated to their caregiving job. They agreed that in some cases, individuals feel more comfortable receiving personal care from family members. At the same time, focus group participants acknowledged that some family dynamics might necessitate care by a non-family caregiver.
- Isolation and lack of a support system is an issue for both family and nonfamily Personal Preference workers. They found that the Personal Preference consultants were not available for assistance.

Participants offered ideas for recruiting personal care workers.

- A registry that would link potential workers and consumers was strongly supported by all participants.
- Group participants suggested several places to recruit personal care workers. They suggested doctors' offices, developmental centers, Salvation Army, churches, unemployment agencies, supermarkets, schools, education departments at local community colleges.

- Participants suggested that recruiting persons with disabilities could provide a potential source of personal care workers, as many of these individuals need jobs and are enthusiastic about helping others.
- Participants agreed that offering health care benefits and more paid hours could help attract people to the profession.

Appendix

Appendix i

Date

Name
Street
City

Dear

I am writing to tell you about a focus group discussion for caregivers whose clients are participating in the New Jersey Personal Preference Program. You may have participated in a telephone survey about Personal Preference that asked you questions about your experience as a paid caregiver for XXX. The group discussions are being held along with the telephone survey to help us learn more from paid caregivers participating in Personal Preference. Some of the topics to be discussed include: Why did you decide to become a paid caregiver? What are the best parts of your job as a caregiver? What do you like the least and/or is the most difficult?

Two times have been scheduled for the focus group discussions: **Monday, May 5 at 3:30 p.m.** and **Tuesday, May 6, also at 3:30 p.m.** The groups will be at the Meadowlands Consumer Center in Secaucus. Each group will consist of 8-10 people. **Food will be served and participants will receive \$50.00 for their time and effort.**

Please note that participation will be strictly confidential. The report will not include any names of caregivers and the employer will not know what was discussed.

If you would be interested in attending one of the groups, please contact Lee Zacharias, the focus group manager at 1-800-589-3583 by **Wednesday, April 16, 2003**. I know that many of the Personal Preference participants have more than one paid caregiver. In these cases, caregivers who provide the most hours and/or days of care will be invited to participate in the groups. If you are selected to participate, you will be contacted with more specific information about the meetings.

Thank you for your interest and support in the Personal Preference Program.

Sincerely,

William A. B. Ditto, Director, State Office of Disability Services
Department of Human Services

**CASH & COUNSELING DEMONSTRATION & EVALUATION
NEW JERSEY PERSONAL PREFERENCE
PAID WORKER FOCUS GROUPS
MODERATOR GUIDE***

Introductions/Warm-up

- ❑ Please introduce yourself and briefly tell us about your family (*to obtain information about the caregiver's other commitments at home*) and about the person for whom you are a personal caregiver.
- ❑ What you think of the Personal Preference program?
- ❑ What do you see as the advantages/disadvantages of a consumer-direction cash option?

Moderator's Note: While the word "relative" is used for the person receiving care, there will be probes for similarities/differences between family and non-family caregivers throughout the group discussion.

On Becoming a Personal Care Worker

- ❑ Have you been a personal care worker before? In an agency? Private setting?
 - If you worked in an agency before how did this come about? In other words, did you take the job in order to be your relative's personal caregiver? [Probe to see if there are any similar situations with non-family caregivers.]
- ❑ 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 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? If so, how many hours do you work in that job?

**The informal language in this guide is intentional to set an informal tone in the discussion groups.*

- Does your client have other paid workers? If so, how many? How many hours do they work?
- Does your client have any unpaid workers? Are they relatives living at home with the client? Others? Have they been able to decrease their hours as an unpaid caregiver? How do you think they feel about providing care and not getting paid while you are?
- Do you see yourselves as “professionals” or is this a “labor of love”?

Moderator’s Note: Discussion in this section will focus on caregivers’ feelings and perceptions about their role as caregivers, while the next section will look more at actual responsibilities. Needless to say, overlap is inevitable.

Moving from Being An Informal (Unpaid) to Being A Paid Caregiver

- Has moving from being an unpaid caregiver to being paid affected your role as a caregiver for your relative? If yes, how so?
- Has becoming a paid caregiver changed your relationship with the person you care for? What about with other family members?
 - How do you think other family members/relatives/friends view your role as a paid caregiver?
- Do *you* feel differently about your role and responsibilities now that you are a paid caregiver? If so, in what ways?
 - Probe: If workers state satisfaction with their role as paid caregiver ask if level of satisfaction is less/more, and why.
- How has participation in Personal Preference changed things for your client?
 - Are there things that he/she has been able to do that were not possible prior to participation in Personal Preference?
 - What aspects of Personal Preference have been most helpful?

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 before Personal Preference, have those tasks changed...how have things evolved?
 - Do you think your client’s expectations of you as a caregiver have changed now that you are paid? [Probe: “Do you think your client might think or say, ‘Now that you are getting paid, you should....’?”]

- Do you have different expectations of yourself now that you are a paid caregiver? [Probe: “Do you say to yourself, ‘Now that I’m getting paid I should....’?”]
- Did you and your client design a “letter of agreement” describing expectations and responsibilities?
- *Do you and your client 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 (a relative or friend who helps the client with Personal Preference tasks such as hiring, managing, and paying a worker)? If so how does the consumer-representative relationship work?
 - What is your relationship like with the representative?
- 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?
 - Are there specific topics/issues/areas of interest that would be helpful to you as a caregiver?
 - How would you like to receive this training...in classes, someone coming to the client’s home, etc.?
- What is your schedule?
 - About how many hours did you provide care prior to becoming paid? What about now? How many hours are you paid for providing care? Have things changed in your day-to-day life?
 - [Probe: Do family members work more hours than non-family members? Do they tend to work more weekends, nights?]
 - [Probe: Do **non-family** caregivers feel that they work more hours than those for which they are actually paid?]
 - 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 or leave another job?
 - Are you able to be flexible in your work schedule? What factors affect your work schedule? [Probe for differences between family and non-family caregivers]

- 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?

On Being a Personal Care Worker

Note: Probe for differences between family and non-family caregivers.

- 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 (for better or worse) 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.)
- If you had a problem as a paid worker, where would you go, whom would you turn to for advice?

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.*