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# Self-Direction and Cash and Counseling: An Overview

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# What are Self-Directed Services?

- Self-directed services are long-term care services that help people of all ages across all types of disabilities maintain their independence and determine for themselves what mix of personal care services and supports work best for them. Self-directed services are sometimes referred to as consumer-directed or participant-directed services.



# Models of Care

## Traditional Model

- professional decision-making
- agency oversight
- rules and restrictions regarding the timing, duration, amount, and scope of services

## Self-Directed Models

- participants have more control over their services



## Cash and Counseling Model

- ✓ One of the most flexible models of self-direction
- ✓ Allows participants the authority to manage a personal care budget
- ✓ support brokers (also called counselors or consultants) provide advice and program information, quality monitoring of services, and informal training in budgeting, planning, and recruiting and hiring workers
- ✓ Participants hire, supervise, and fire their own personal care workers (including relatives)
- ✓ Participants may purchase other personal assistance goods and services.

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# Important Roles in a Self-Direction Model

- Participant
- Representative
- Support Broker
- Bookkeeper or Fiscal Management
- Paid and Unpaid Workers

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# Cash and Counseling Demonstration and Evaluation

## Funders

- The Robert Wood Johnson Foundation
- US DHHS/ASPE
- Administration on Aging

## Waiver and Program Oversight

- Centers for Medicare and Medicaid Services

## National Program Office

- University of Maryland (CCDE)
- Boston College Graduate School of Social Work (CCDE Replication)

## Evaluators

- Mathematica Policy Research, Inc.
- University of Maryland, Baltimore County



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# Cash and Counseling Demonstration and Evaluation

Over 5500 elderly and adult Medicaid consumers in Arkansas, Florida and New Jersey participated in a real world test of this model in which participants manage their own budgets (there were also about 1000 children with developmental disabilities enrolled in Florida's program)

Half were randomly assigned to manage their own budgets (C&C participants), while the remainder used traditional agency-directed services. Use of representatives by C&C participants ranged from 47 to 70 %.

Almost all participants choose to use agencies to handle financial management and payroll.



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# Cash and Counseling Demonstration and Evaluation

C&C participants were highly satisfied, and 85-98% said they would recommend the program to others.

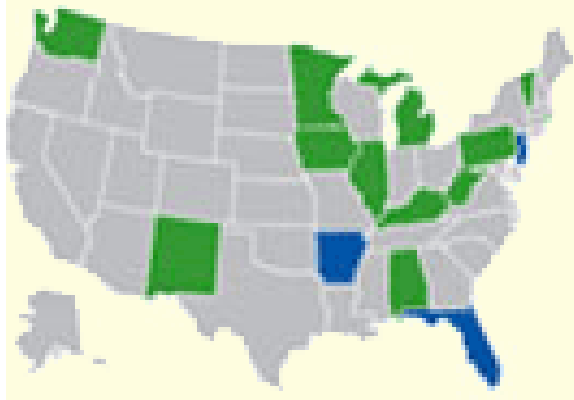
C&C participants reported more flexibility, control and greater satisfaction with overall quality of life and experienced similar or better health outcomes

Over time, the C&C model has been shown to generate program cost savings by reducing institutional care

Reports also suggest that this model of service is successful for individuals with diverse disabilities, including those with physical disabilities as well as those with dementia and other mental health diagnoses.



# Demonstration States and Expansion States



- Demonstration
  - Arkansas
  - Florida
  - New Jersey
- Expansion
  - Alabama
  - Illinois
  - Iowa
  - Kentucky
  - Michigan
  - Minnesota
  - New Mexico
  - Pennsylvania
  - Rhode Island
  - Vermont
  - Washington
  - West Virginia

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# National Resource Center for Participant Directed Services

Center was launched in April 2009 and funded by:

- ❑ The Robert Wood Johnson Foundation
- ❑ The Atlantic Philanthropies, with additional support from:
  - U.S. Administration on Aging
  - Office for the Assistant Secretary for Planning and Evaluation
  - Veterans Health Administration
- Housed at Boston College Graduate School of Social Work



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# **NRCPPDS Mission**

To infuse participant-directed options into all home and community-based services by providing national leadership, technical assistance, education, and research, leading to improvement in the lives of individuals of all ages with disabilities.



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# Self-Direction: Expanding Beyond Medicaid Populations

- NRCPDS Partnership with U.S. Administration on Aging: Initiative to promote culture change from “professional” to “empowerment” approaches to services and supports
- NRCPDS Partnership with U.S. Administration on Aging and Veteran's Administration: Initiative to create a network of veterans-directed services programs in every state
- NRCPDS Environmental Scan of Behavioral Health and Self-Direction and current demonstration project.





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# Hearing All Voices: Negotiating the Needs of Participants with Dementia and their Care Team Members

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# Presentation Overview

- Problem statement and significance
- Research questions
- Methods
- Survey and interview findings
- Discussion and training recommendations
- Policy implications

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# Problem Statement and Significance

- Participant-directed (PD) services focus on the needs and preferences of the people needing services, and it is also important to respect the needs and wishes of all care team members.
- At times the participants' needs and preferences may conflict with those of other care team members (representative, paid/unpaid workers). To honor the needs of all team members and prevent caregiver burnout, it is important to “hear all voices.”

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# Problem Statement and Significance

- Representatives need to know how to identify participant requests, including those that extend beyond other care team members' abilities and boundaries. They also need skills to negotiate such differences.
- They must be able to train paid/unpaid workers to manage these issues. These skills are important when caring for people with dementia as their requests, understanding of appropriate boundaries, and ability to understand negotiation are likely to change over time.

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# Problem Statement and Significance

- Evidence-based training materials developed for families caring for people with dementia have not focused specifically on the PD model.
- Training materials designed for the Cash & Counseling model have not addressed the special needs of representatives for people with dementia.
- Specific training and support for this essential role may improve the effectiveness of those who choose it – making a good program even better. It may also encourage more to choose this path.

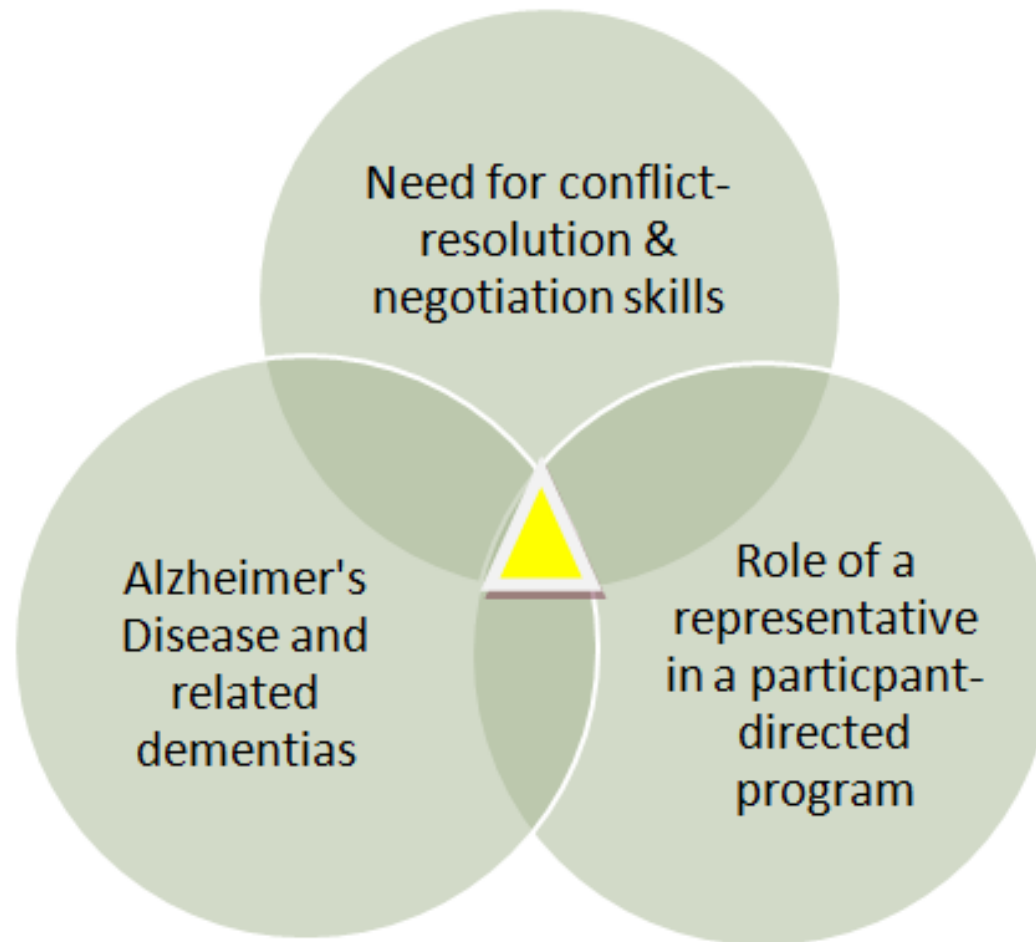
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# Problem Statement and Significance

- This study built on three previous studies addressing care teams for participants with dementia in a PD program.
- It focused on the representative's role in conflict resolution and negotiation, and identified training needs to assure that representatives obtain these skills.

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# Representatives for Participants with Dementia and their Need for Negotiation Skills



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# Research Questions

- 1) How do representatives describe their need to address differing views and preferences among participants with dementia and other care team members in a PD program?
- 2) What are the training needs of representatives to help them negotiate differing views, needs, and preferences among participants with dementia and other care team members in a PD program?

We answer the research questions with quantitative and qualitative methods. The qualitative data may inform survey findings or reveal additional information.



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# Quantitative Methods

- We selected survey questions that reflect representatives' management and coordination of multiple points of view.
- The two previous presenters described the survey data collection and analysis methods.

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# Qualitative Methods

- This study included the previously described open-ended interview questions, including questions about conflict and resolution and ways to know participants' needs.
- Interview data collection and analysis methods were described in the two previous presentations.
- The qualitative analysis (using MAXQDA 10) included any reference in the transcripts to conflict resolution or negotiation skills identified in our framework.

# Survey Findings

In your role as a representative, how well prepared do you think you are to:

- Represent the participant's decisions and preferences even if they are different from your own? 3.17 (.648) 9/30 = 0.30
- To ensure that the paid caregiver has the skills to respond to his/her behaviors? 3.30 (.702) 13/30 = 0.43
- Understand and negotiate the views of both the participant and his/her care team? 3.37 (.669) 14/30 = 0.46
- To ensure that the unpaid caregiver has the skills to respond to his/her behaviors? 2.73 (1.048) 7/30 = 0.23
- To take care of yourself? 3.53 (.681) 19/30 = 0.63

- \*Numbers represent mean scale score, (SD), raw number and percent “very well prepared” 0= “not at all prepared” 4= “very well prepared”



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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

Representatives addressed many themes related to different views and preferences and the need for conflict resolution.

- Findings are organized by participant and care team relationships (i.e. participant and others, representative and others).
- The area of conflict and underlying theme for the conflict may be related to the participant, care team members, or both.
- Conflict could result from the participant's behavior, the representative or care team members' behavior, or the combination (i.e., how the participant, representative, and care team members respond to one another).
- Findings include multiple perspectives.

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Representative
  - ❑ Theme: Conflicts about care, comfort, and safety.
  - ❑ May pertain to the participant, care team members, or both (i.e., the care needed, how it's provided, comfort and safety for the participant and care team).
  - ❑ *“Sherman, you cannot drive...Because he would just get so mad. And he ended up actually ... causing a wreck and hitting a state trooper ... and he actually ended up spending the night in jail...”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Representative
- Theme: Representatives explained that conflicts could result in anger, arguments, lying, resistance to care, and other difficult behaviors.
- “... *you don't argue with somebody who really doesn't know what you're saying .... that doesn't do any good. So I've learned to, when I can, just to agree with him.*”
- “...*she locked my keys in the house and wouldn't let me get them*”

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Representative:
- Theme: Representatives reported participant autonomy and finances as areas of conflict.
- *“Mentioning anything financial to her (is a mistake).... she don’t understand we’re back to where flowers should be a penny.” ....*
- *“Well sometimes she gets angry at them if they don’t let her...go out – she loves to go out on the front porch. ... she was being kinda ugly because it’s so hot they told her she couldn’t go out and it made her mad.”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Caregivers (including other Family Members)
- Theme: Representatives identified difficulty around personal care (e.g., bathing, eating), autonomy, safety, and comfort. The conflict about personal care may be due to a lack of caregiver training to help perform these tasks for people with dementia.
- *“...he don't like to put clothes on, ...bathe. ... the person that takes care of him got to be kind of forceful with him”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Caregivers (including other Family Members)
- Theme: Participants and caregivers may have different goals.
- Caregivers may not understand PD principles. Representatives reported that these issues may lead to conflict, difficult behavior.
- *“I think my Momma pushed her cause my Momma said she didn’t like her”*
- *“... when we were tryin to get her ready to go to the doctor I had them to get her ready ... and she gets mad at them when they put her in the shower ... and she says she doesn’t need to change clothes ...she really gets mad at them and tells them to leave and never come back...”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Participant and Caregivers (including Other Family Members)
- Theme: Representatives reported that other family members may not understand dementia behavior, and may lead to confusion and anger among parties.
- *'Every once in a while ... they'll get mad at him, or they'll get upset, and I'll have to remind them, 'You know grandpa doesn't always mean what he says,' and then we talk about it.'*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Caregivers (including Other Family Members)
- Theme: Representatives spoke of conflicts about how to manage dementia behavior and work issues (e.g., the type, amount, and how work gets done).
- *‘He don’t want to eat certain things don’t make him eat it. ... when he don’t want to take no bath, just leave him alone, and finally he’ll decide it on his own.’*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Caregivers (including Other Family Members)
- Theme: Representatives identified the need for more team work and better understanding of the disease process. These issues led to uneven distribution of work in the family.
- *“... sometimes you have to teach people how to how to be part of the team. And that takes patience.”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Caregivers (including Other Family Members)
- Theme: Representatives referred to unsupportive family members and disagreements about care. Differing values and limited understanding about the disease process led to conflicts.
- “ *the ones that don't do it* (family members who don't help with care) *are the ones complaining about the people that do*”

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Caregivers (including Other Family Members)
- Theme: Representatives discussed ways to avoid family conflict with difficult decision-making, including legal agreements.
- *“.. we went to a lawyer and got everything in writing of her wishes and she don't want life support and that kind of stuff. ... there's no dispute among family members there.”*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Health Care Professional
- Theme: Representatives spoke of conflicts about the participant's care, safety, and comfort, as well as difficulty around taking medications and driving.
- *The family physician and neurologist ...and they had all said, '... do not drive.' ... 'you need to take the keys away, he cannot drive.' ... you can't just go up to somebody and say 'you can't drive anymore' and take their keys away."*

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## Interview Findings: Representatives' Needs to Address Differing Preferences Among Care Team Members

- Views and Preferences between the Representative and Health Care Professional
- Theme: Representatives spoke about limited communication and understanding about medications.
- *“... I don't have any other than the prescription label what the drug is for and how often to take it. ... it's very limited information ... And even his conditions ... like how does that really affect his system.”*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Knowledge of dementia symptoms, including behavioral issues
- Representatives discussed ways in which to address confusion and misinformation, when participants with dementia might become agitated if someone corrected them.
- *“So if we’d known that right off hand how to talk with her and everything it’d probably have been easier for them and for me.”*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Knowledge of how to train caregivers to provide personal care for participants
- Representatives' assessment of their preparedness for this role varied.
- Survey respondents reported feeling more prepared to train paid vs. unpaid caregivers to respond to the participant's behaviors.
- *"...you gotta stay calm, ... You have to ... be cheerful and confident about what you're doing so you don't relay any negative vibes to them."*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Communication techniques including conflict resolution and negotiation skills
- Representatives spoke of communicating with a family member with dementia, specifically around persuading the person to complete a task. Approaches varied from gentle persuasion to more forceful interactions.
- *“When her attitude gets a little sour ... I know that she needs something, and ... she’ll have a hard time finding the words ... you watch her body, watch her eyes, and try to put the puzzle together of what they’re saying...”*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Teamwork and team-building
- Representatives discussed the importance of working as a care team to help one another and provide the best care possible for their family member with dementia.
- *“Just having a team around that can get what I need when I need things for him. ... I do have a team that I can call and they help me out with basically everything I need to take care of Daddy.”*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Importance of having family available.
- Having back up helped prevent nursing home placements.
- *“So that’s the main reason I haven’t put him in a nursing home because they told me they’ll help me with him whenever I need em. I do have my oldest sister and younger brother ...”.*

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## Interview Findings: Training Needs of Representatives for Participants with Dementia

- Theme: Representatives identified approaches to working with team members, including the physician and other health professionals.
- *“I just talk to the one that is taking care of them ... making sure they are doing the things they are supposed to and it does take a load off of me ... that has helped ... tremendously.”*
- *“... basically get information through my doctor...I go to my doctor and tell him what the problem is...he will find out what I need and get it for me”*

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# Discussion and Recommendations for Representative Training

-Survey findings and interview data clearly indicate that, although many representatives of participants with dementia in a PD program feel very prepared for their complex tasks, they can benefit from more and different types of training.

-Representative training needs to incorporate information from existing programs (e.g., Alzheimer's Association).

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# Discussion and Recommendations for Representative Training

Potential results of expanded training for representatives of participants with dementia include:

- ❖ Greater understanding and respect for roles within the care unit (i.e., “hearing all voices” involved in this complex team),
- ❖ Greater understanding and respect within families caring for a relative with dementia,
- ❖ Greater autonomy for participants,
- ❖ Fewer difficult behaviors among participants with dementia, improved safety and care, and
- ❖ More appropriate expectations among care team members.

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# Discussion and Recommendations for Representative Training

Points to consider in designing training for representatives:

- 1) Expect some conflict within the care team. Learn how to “hear all voices,” and successfully negotiate differences among care team members.
- 2) Expect change and the need for fluid problem-solving.
- 3) Learn to support team members’ strengths and forgive their weaknesses.
- 4) Address multiple reasons for sibling conflict.
- 5) Address reversing roles among adult children and parents as well as among spouses.
- 6) Address the need to focus on high priorities and “let go” of smaller items.
- 7) Address financial aspects of caregiving.

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# Policy Implications regarding Representative Training

Training for representatives caring for participants with dementia can support policy goals in health care reform and the Long-Term Care Commission designed to:

- Encourage more PD services for a growing number of participants with dementia;
- Enhance the effectiveness of PD services for these participants, who can benefit from the flexibility of a cash option to meet their changing needs; and
- Encourage more family-centered services by supporting the critical role of representatives and family caregivers.

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# Conclusion

We welcome comments.

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