Research Results: How to Improve Medicaid's Money Follows the Person Program for People Living with Dementia

We are sending you this summary of our research study because you participated in an interview, focus group, or survey, or supported this project. Thank you very much for your participation and help to identify how to improve the MFP program. In addition, we are grateful to the Connecticut Department of Social Services, the CT Long-Term Care Ombudsman Program, Statewide Family Council, Resident Council Presidents, and Nursing Home administrators, activity directors and social workers for their overall support of this project.

- Ellis Dillon, PhD and Julie Robison, PhD (Principal Investigators) UConn Center on Aging

What is Money Follows the Person (MFP)?

- Medicaid's Money Follows the Person (MFP) program helps eligible individuals move out of institutions into the community. Connecticut is a national leader in the MFP program.

Why did we focus on people with dementia in our study?

- The number of people with dementia is growing, especially in nursing homes.
- People with dementia are less likely to use the MFP program, but we do not know why.
- We need to better support individuals with dementia who want to live in the community.

What did this research study do?

- We interviewed 44 older adults eligible for MFP, 44 family members, and 50 professionals.
- A statewide survey was completed by 242 professionals involved in the MFP program.

The most frequently reported barriers to MFP applications reported by professionals:

1. The family or conservator wants the person to stay in the nursing home
2. Lack of awareness about the MFP program
3. Concerns about social support in the community
4. Lack of accessible or affordable housing

What did a survey of professionals tell us about MFP for people with dementia?

- 86% agreed people with dementia face additional safety challenges and risk of harm
- 73% agreed people with dementia need more hours of paid support than MFP can give them
- 73% agreed increasing participation in MFP for people with dementia is important
- 67% agreed the MFP program only works well for people with dementia if they have family members who can provide unpaid support in the community

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What did we learn about how the MFP program works for everyone?

- ***Many eligible residents and families have never heard about MFP***. Residents, family members, and nursing home staff need more information about MFP, how it works, and who it can help.
- ***Nursing home social workers play a key role in influencing who learns about the MFP program.*** They vary in how much they support and refer people to the MFP, and social worker turnover is high.
- ***Desire to move matters***. Some people prefer to stay in the nursing home, because of social connections and support in the nursing home or concerns about lack of social connections and support in the community.
- ***The ability to advocate for yourself and do paperwork makes the MFP process much easier.***
- ***Professionals said it is important to clearly communicate*** with nursing home residents, their families, legal guardians, and nursing home staff about expectations about the process, the status of individual cases, and the preferences and needs of individuals.

> **"And I was in no condition at that time and I'm in no condition now to try to reach out to strangers and ask for a place to live."**
> Older adult without dementia, applied to MFP but never moved

- ***Greater medical and support needs can make a move difficult or impossible*** due to limited budgets and rules about what in-home paid staff are not allowed to do (e.g. inject insulin). These challenges are especially common among people who need help with mental health, substance use, two-person support, or diabetes.
- ***Lack of appropriate housing is a major obstacle***. The loss of housing while in a nursing home and the difficulty finding accessible, affordable, and available housing delays moving to the community or leads people to never move out of the nursing home.
- ***Family support makes a big difference***. People are more likely to move if their family members want them to and have the money, time, and ability to help before, during, and after the move.
- ***Older adults and families have limited awareness of community resources and support in general,*** including knowledgeable professionals, and community resources such as agencies on aging, senior centers, family councils, and addiction support.

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What did we learn about people living with dementia and MFP?

- ***People with dementia are often admitted to a nursing home later in their illness*** and often need more support at home than MFP or their families can provide.
- ***They have a harder time advocating for themselves and managing paperwork***.
- ***Family support can be more challenging*** due to the need for 24/7 care, caregiver burden, and caregiver health. Caregivers may be more likely to think it is better for the person not to move.
- ***They can have greater medical and support needs*** making it harder to live in the community.
- ***Safety risks and supervision needs prevent them from moving to the community.***
- ***Professionals agree it is harder to plan for and assist them to move to the community*** because it takes more time, coordination with other professionals and family, and safety planning.
- ***Housing is more difficult to find*** because they often require specific unit features to ensure safety and more assistance to find and maintain housing.
- ***Despite challenges, many people with dementia are successful in using the MFP program***. People with family support, lower support needs, and who already have housing are more successful.

"My daughter heard about this. And she facilitated my move. If it wasn't for my daughter, I wouldn't be here." Older adult with dementia who moved with MFP

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Recommendations to improve MFP for everyone including people with dementia

- **Increase program awareness and outreach** to nursing home residents, families, and staff.
- **Better coordination and communication** about the MFP process among residents, families, and professionals.
- **Prevent loss of housing** by planning for return to community at nursing home admission.
- **Improve affordable housing**, supportive housing, and community housing solutions.
- **Increase training on dementia care** strategies for nursing home and MFP staff and families. Respondents suggested dementia training should be targeted at behaviors (e.g., sundowning), how to manage someone with dementia, becoming more familiar with how best to approach someone with dementia so you are not confrontational, etc.
- **Improve support networks**, local partnerships, and community supports for older adults and family care partners.
- **Support families to increase their capacity to care** for older adults by offering education, planning assistance, and resources that enable families to help or continue providing care.
- **Provide advocacy and logistical support** through case managers, peer advocates, and ombudsmen, and assistance with phone calls and paperwork.
- **Use technology and virtual/telehealth supports** to provide an extra layer of support beyond in-person support from family or paid staff.

Based on what we learned in this research, our team is working with the Connecticut Department of Social Services on how to improve MFP. If you have any questions please contact MFPstudy@uchc.edu

Study title: Increasing successful returns to community living from nursing facilities through Money Follows the Person program: Mechanisms for improving outcomes for older adults with dementia

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