



## **Service Providers**

### **Stakeholder Group Interviews**

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Prepared by:  
**RTI International**

Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.



**Interview with Service Providers Stakeholder Group**  
**Co-Chairs Sarah Lock and Douglas Pace**  
**July 27, 2017, 3:00–4:00 pm ET**

**Interview Questions**

1. What are the main concerns of this stakeholder group in relation to care and support services for people with dementia and their caregivers?
2. There are many types of services and supports for people with dementia and their caregivers, including education programs, training on caregiving skills, counseling/support, respite care, home modification and other safety services, and support in navigating medical care and other supports. What services and supports do members of the group think are most effective for people with dementia? For caregivers? Are there any that are less important or helpful?
3. How do members of this group define “effectiveness” when it comes to services and supports? What kinds of outcomes or results are most meaningful for people with dementia? For caregivers? What research is needed to test those beliefs about effectiveness?
4. What level of evidence do you need to see before adopting or funding an intervention? What criteria do you use in selecting programs or approaches to fund or deliver?
5. Among people with dementia, are there groups whose experience needs to be better understood? What do we need to know?
6. Among caregivers, are there groups whose experience needs to be better understood? What do we need to know?
7. What do we most need to know to better serve people with dementia and their caregivers? What questions should researchers be asking?
8. Are there any topics related to care and support services that generated a lot of debate or discussion within your stakeholder group? If yes, what are the topics, and how would you describe the different positions or ideas that have been shared?
9. Have there been any topics of discussion or ideas that have surprised you?

## **Summary of Service Providers Interview**

### **1. Collaboration**

Services and supports for people with dementia and caregivers need to be better integrated among providers. This integration needs to occur within the continuum of long-term services and supports (LTSS) and between LTSS and acute care providers. Providers are just starting to think about how to do this. They are considering a variety of issues, such as LTSS providers' relationships to managed care organizations and accountable care organizations (ACOs) and how to work with them, including how to develop partnerships between organizations to better connect people with the services they need. Another issue is technology and how it can be used to help integrate care through electronic health records and linking LTSS to acute care systems. There is also an increased appreciation among hospitals of the importance of LTSS and how those LTSS services can improve both quality of life and cost effectiveness.

Challenges to developing partnerships remain, however. Although this is starting to change, some hospitals remain resistant to working with LTSS. Having ACOs hold hospitals accountable for outcomes may help. There also remains a divide between academic research and practice. Past research and measures have not always been tied to the practical realities of service providers. For example, it may not be feasible for an aging services organization to deliver an in-home intervention that requires 10 visits or to conduct assessments every month.

*Questions to inform research:*

- How can hospitals and clinics incorporate information about LTSS referrals and usage into health records?
- How can health care providers use electronic health records to facilitate communication among various providers?
- How can hospitals continue to build stronger connections with LTSS providers? What would encourage these partnerships?
- How can researchers and services providers work together to advance practical, evidence-based interventions?

### **2. Return on provider investment**

There is general agreement on the triple aim: better health, better health care, and lower costs. To make this happen, providers need to know what to invest in. Better quality of care and quality of life are the goals, but provider activities must be sustainable financially. Much more research is needed that ties services to costs and benefits. Without the data showing that money can be saved through different care approaches, most providers are not going to make changes.

Much of the work that is being done on developing new care models is being funded through charitable dollars or government. Going forward, these new models must be self-sustaining, especially as growing numbers of people are relying on these systems. There must be enough

money in the system to reimburse people for their work and for providing people with necessary training.

*Questions to inform research:*

- How can we encourage more research on cost-effectiveness of various care and service approaches?
- Which interventions save money?

### **3. Outcome measures**

The group has extensively discussed outcome measures. Although the group has not identified which measures should be used, they agree that it is possible to develop a “gold standard” of consistent measures that can be used by researchers and providers. These measures need to consider the progressive nature of the disease and address what quality care and quality of life mean at each stage of the disease. For example, institutionalization might be one measure, but staying at home forever is not necessarily an appropriate goal for persons with advanced dementia, so the standard needs to be adjusted to account for the realities of the disease.

The group has also discussed the importance of incorporating these measures into everyday operations of service providers. The practice of incorporating ongoing quality measures is still in its infancy in LTSS. Again, costs need to be incorporated into the evaluation of services and practices to assess return on investment and sustainability.

### **4. Developing a dementia-capable health system**

Providers want to improve quality of care and quality of life for people with dementia and their families, but there are questions about how to take successful practices and develop the evidence to support their wider dissemination. There is also much to learn about how to take evidence-based interventions and to disseminate them broadly and sustainably. Again, this group has emphasized that what quality of life means may differ depending on the stage of the disease, but person-centered practices are central to good care at all stages. Palliative and hospice care are of particular importance in serving people with dementia.

*Questions to inform research:*

- How can evidence-based interventions be disseminated broadly and sustainably?
- How can palliative care be better integrated with care throughout the disease continuum?

### **5. Groups that need greater focus from service providers and researchers**

The service providers’ stakeholder group has identified several groups whose experiences with dementia may be unique and who need greater attention:

- *People in the early stages of dementia*

By the time people with dementia are using LTSS, they are generally in the mid to late stages. We need to know more about the needs of people in the early stages of the disease.

- *People living alone with dementia*

There are many people living alone with dementia. There has been much focus on caregivers but less on people who do not have caregivers. We need to think about how best to train first responders to work with this group.

- *Lesbian, gay, bisexual, transgender and queer (LGBTQ)*

We need to know more about the specific needs of older LGBTQ adults with dementia.

- *African Americans and Latinos*

These groups are more likely than whites to have dementia. We need to understand their needs and how to serve them.