



State Programs

Stakeholder Group Interviews

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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 State Stakeholder Group
Co-Chairs David Hoffman and Helen Matheny
August 10, 2017, 1:00–2:00 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 State Stakeholders Interview

1. Developing a dementia-capable health care system

Workforce competence and skill

Primary care providers play a key role in maximizing the well-being of persons with dementia and their caregivers. Public health officials need to help ensure that primary care providers have the information and training they need related to early identification of dementia, available community resources, and care coordination. Many primary care physicians are using outdated information, but it can be difficult to disseminate new findings and practices in a way that encourages adoption.

One area where primary care physician training is critical is in differential diagnosis. Determining the cause of dementia, whether it is vascular dementia, Alzheimer's disease, dementia with Lewy bodies, or some other form of dementia, is very important in obtaining appropriate treatment and support and developing a care plan. Currently, it takes a lot of time, effort, and persistence by people with dementia and their families to get an accurate diagnosis. Improved physician training is needed.

Specialty care

Primary care physicians need to understand when it is appropriate to engage specialty physicians. Another issue related to specialty care is the shortage of geriatric specialists, which is projected to worsen in coming years. Some of this shortage is caused by the lower earning potential associated with this specialty.

Care delivery approaches

Medical care for people living with dementia can be complex and is often compounded by the presence of other chronic medical conditions which require time-intensive management by health care providers. The existing health care delivery system, built around 15-minute appointments, is not suited to the type of care that this population needs. Short appointments are not sufficient for providing any meaningful education or making referrals to other services. We need to look more at how care is being delivered and how the education and supports that people with dementia need can be provided most efficiently and effectively.

One opportunity for improving care is to educate physicians on medical billing options that can maximize reimbursement for the extra time spent with patients and families. This is an approach New York has taken, educating primary care practices on coding practices.

Questions and issues to inform research:

- What are the most effective strategies for incentivizing health care professionals to acquire new knowledge? Simply providing information is not sufficient. Does enhanced reimbursement motivate health care professionals to acquire new knowledge?
- What are the most promising practices in improving quality of care for people with dementia?
- How can we share and replicate those practices among states?
- Who within the health care system would be most effective in providing the education and referrals that people with dementia and caregivers need?
- How can we attract more medical professionals to geriatric specialties? What changes to the education system and payment structures are necessary?
- What changes in salary, fringe benefits, working conditions, and career path would recruit and retain more people to be direct care workers?

2. Dementia care quality indicators

Developing metrics

The state stakeholder group has spent considerable time discussing ways that states can best obtain and use data to improve outcomes related to dementia care. One challenge is that there has not been a set of agreed-upon metrics for assessing dementia care. The group hopes that the Care Summit will be an opportunity to accelerate the development of metrics, or at least identify a process for determining metrics.

Any quality indicators developed for dementia care need to be linked to metrics that the Centers for Medicare & Medicaid Services (CMS) already tracks. We should look at what indicators are in place through CMS and then consider additional indicators that can and should be added, such as Statewide Planning and Research Cooperative System (SPARCS) hospital discharge and emergency department data and state-added Healthcare Effectiveness Data and Information Set (HEDIS) measures. CMS is also developing electronic clinical quality measures for cognitive impairment screening that will document not only impairment but contact information for a care partner.

Determining how to obtain and use data

The state stakeholder group has discussed existing databases that state officials use for a variety of purposes and how those could support improved dementia care. Some of the possible data sources discussed include HEDIS, which is the primary data set used within managed care (some states add additional measures); SPARCS, which provides data on hospital and emergency department discharges and in most states and goes back for many years; and the Behavioral Risk Factor Surveillance System (BRFSS), to which optional

cognitive impairment and caregiver modules can be added by states. Many states need help knowing which data to use and how.

Changing clinical practice

There is potential to change clinical approaches via improved data. One example occurred in the 1990s, when a group of state public health officials added some key measures to HEDIS, reflecting recommendations of the U.S. Preventive Services Task Force related to management of hypertension and diabetes. According to the stakeholder group co-chairs, this change in data collection led to a change in patient outcomes. A significantly higher percentage of people with these conditions were being treated according to acceptable guidelines after these measures were added.

Currently, some states are using the cognitive impairment and caregiver modules on the BRFSS survey. Resources to support this additional data collection are insufficient or absent in some states. In some cases, states seek private funding, for example from nonprofit organizations, to support this type of data collection effort. Good public policy dictates that availability of critical data not be dependent on inconsistent sources of support.

Although people with multiple chronic conditions, including dementia, present a challenge to the health care system and to public agencies that must find ways to pay for their care, the fact that their care is resource intensive also presents an opportunity. Because of the high cost of their care, people with dementia are increasingly gaining the attention of state Medicaid agencies. This creates an enhanced level of interest on the part of state public health officials when it comes to improving quality of care and simultaneously reducing excessive expenditures.

Federal and state resources and priorities

Despite broad agreement that Alzheimer's disease and related dementias and related caregiving issues are a major public health priority, the federal government has not made sufficient resources available for states to implement standardized data collection. We have seen with other health problems that when the federal government makes an investment, states can develop a consistent approach to addressing a problem, but that the absence of federal funding ensures inconsistency. For example, federal funding could enable the addition of the cognitive impairment and caregiver BRFSS modules across all states. Consistent data is very important to policy making. Currently, there is wide variation among states in the data that they are collecting and the investment of resources in staff time and focus on this issue.

Also, some states are more focused on other health priorities and have not created specific positions with responsibility for dementia-related data and reporting. Unless there is a specific person assigned, it will not happen. The group recommends that every state have a liaison and that there be a state entity responsible for the implementation of

the Alzheimer's plan. This could help facilitate opportunities for states to learn from each other, for example sharing data and promising practices.

Questions and issues to inform research priorities:

- What is the quality of care being provided to people with dementia throughout the country?
- Which measures should be added to CMS's list of quality indicators?
- How can states be involved in developing a common database and sharing information with other states?
- Which data sets can best be used to help assess dementia care? Possible options include HEDIS, BRFSS, and SPARCS.
- What kinds of support and assistance do states need in understanding how to use data to improve dementia care and support?

3. Collaboration

Among states and national organizations

States' differing levels of investment in dementia care and support present a challenge in terms of advancing quality of care nationally. However, it also creates an opportunity for states that have not yet invested in dementia services to learn from states that have already developed such systems and to avoid some predictable challenges.

Discussions among state officials can also be used to help move dementia priorities forward. For example, the National Association of Chronic Disease Directors has an interest group related to people with dementia and caregiver health; this group is considering potential partnerships with other groups of state leaders, such as the National Association of Medicaid Directors or National Conference of State Legislators. State officials should consider engaging these kinds of national partners as a forum and vehicle through which cross-state activity can take place.

Within states and local communities

In many states, the Medicaid agency, which is one of the primary payers of long-term services and supports (LTSS), operates as a silo, with little linkage to other state government agencies. Medicaid is already paying for LTSS for people with dementia and for caregivers, who often have chronic conditions as well. These groups are expensive users of medical services.

Many people with dementia are eligible for both Medicaid and Medicare. The high costs of these plan participants may help incentivize Medicaid agencies to collaborate more closely with other state agencies serving older adults. It may also cause them to

encourage improved collaboration between the clinical community and other community agencies like the Alzheimer’s Association.

Questions and issues to inform research priorities:

- What are the best ways for states to build connections among themselves and to collaborate in sharing information and learnings with each other?
- How can community agencies, clinical care providers, state agencies, and federal organizations form partnerships to foster improvements in dementia care?
- How can states identify the most promising evidence-based services and practices, and how can they support translation of those services into widespread practice?

4. Groups that need greater focus from service providers and researchers

There are many groups of traditionally underserved people whose needs for dementia care and support services are not well understood. These groups include African Americans; Latinos; lesbian, gay, bisexual, transgender and queer; and non-English speakers. Specialized outreach is often necessary to locate these groups and provide them with services. An additional challenge is that in some cultures, people may not identify themselves as “caregivers” but may see what they are doing as simply an extension of their familial responsibilities, and therefore they are unlikely to seek support. There is also much that is not known about how the impact of dementia may vary among different groups.

Other groups that need to be more closely studied include the following:

- People with dementia who live alone.
- People with early onset dementia—This is a relatively small group, but one that has significantly different needs and experiences than older adults diagnosed with dementia. The experience of their caregivers may also have little in common with traditional caregivers. The dementia often advances more rapidly, and these families may have younger children still in the home and face a greater financial impact because of the loss of employment.
- Rural populations.
- Children involved in providing care to someone with dementia.

Questions and issues to inform research priorities:

- What types of services do people living alone with dementia need? How do their needs differ from people who live with someone?
- What are the barriers to providing access to care to rural populations?
- How many children provide care to someone with dementia? What is the impact on the children of providing care?