



Final Recommendations on Outcomes that Matter

Stakeholder Group Paper

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Prepared by:
**State Government Programs
Stakeholder Workgroup**

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.



National Research Summit on Care, Research, Services and Supports
State Programs Stakeholder Group
Final Recommendations on Outcomes that Matter

- 1. Options for financing strategies for LTSS.**
- 2. Research informing public policy and insurance policy.**
- 3. Need for translational research that puts intervention into practice.
Develop and test interventions**
- 4. Prevalence of substance use as a coping strategy among caregivers.
Substance use impacts both caregiver and care recipient health and well being.**
- 5. Increase Latina caregivers in accessing and receiving supports and services for themselves. Research how Latina caregivers can recognize themselves as a caregiver beyond their perceived gender role.**
- 6. Research the ways home care workers can be trained on caregiver needs, health and well-being while receiving training on dementia care.**
- 7. Identify and put into practice those resources/interventions that result in more underserved families accessing optimal and evidenced based care.**
- 8. Research effectiveness of primary care interventions that address caregiver needs through screening, education and support while providing screening and care to patient with dementia.**
- 9. Research that would result in home care workers earning a living wage. An ample workforce allows people with dementia to remain at home longer, especially those residing in rural areas. This would also alleviate caregiver burden of day to day care of patient.**

Notes from the Chronic Disease Directors' Alzheimer's Interest Group Conference Call Related to National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers

March 23, 2017

The call was facilitated by: David Hoffman, New York; Jennifer Mead, Oregon; and Helen Matheny, West Virginia, Co-Chairs of the Summit State Programs Stakeholder Group.

Representatives from the following states participated in the call: AZ, CA, GA, KS, MD, NC, UT, VT, VA, OR

Unmet needs and problems with dementia care, services, and supports that need research as identified by call participants.

- There are obstacles in clinical care, i.e. pressure for time. The intersection of clinical care and community-based services creates obstacles on both sides and is worthy of research. Could the dual demonstration project in California be a model for addressing this obstacle? How well is it working? Is it meeting the needs of underserved populations?
- In regard to coordination of care there needs to be more research related to underserved populations: Latino and Indian population, women, individuals with disabilities, hearing and visually impaired.
- Another big issue is that people are not receiving a diagnosis. People feel as though physicians are not giving diagnosis. Additional research should be conducted as to why are people not receiving the diagnosis and why people not seeking a diagnosis.
- Research should be conducted to determine if actions such as implementing clinical guidelines and/or utilizing toolkits would help primary care providers make an early diagnosis of Alzheimer's disease or a related dementia.
- Research is needed to explore why the new code (G0505) related to care management is not being utilized.
- Do primary care providers have the skills, competencies and knowledge to evaluate a cognitive assessment?
- Other topics for additional research are dementia friendly communities and public health. For example, are there effective worksite policies that are supportive of caregiver issues?
- Can public health initiatives related to healthy eating and increasing physical activity help reduce the risk for onset of dementia?
- End of life issues need for research and more discussion.

- Research is needed to determine effective strategies to assist individuals who show up to an emergency department who warrants further evaluation. What is the best way for the individual to be evaluated for cognitive assessment while at the same time making sure the individual is not lost in the system?
- Could the state of New York Centers of Excellence (with diagnostic expertise, caregiver support and follow up related to medications) be a model that should be replicated?

Notes from State Aging & Dementia ADSSP Grantees Conference Call Related to National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers

March 27, 2017

The following individuals and their organizational affiliations are as follows: Kaylene Way, Ohio Dept of Aging; Sally Steiner, Michigan Aging & Adult Services Agency; Devin Bowers, Virginia Dementia Services Coordinator; Danni Atkins, Florida Dept of Elder Affairs; Peggy Spaulding, Colorado State Unit on Aging; Leisa Easom, Rosalynn Carter Institute for Caregiving; Debra Cherry, Alzheimer's Greater Los Angeles; Helen Matheny, West Virginia University Health Sciences; Jennifer Mead, Oregon State Unit on Aging

Issues identified where more research would be helpful:

Evidence-based interventions

- Interventions that are appropriate for low-literacy populations, different cultures, and different language groups. One size does not fit all with existing interventions. The 'footprint' has changed from fee for service to fee for outcomes.
- Interventions that work for very rural populations, taking into account both those being served (issues of isolation, fragmented care and services, small populations, distances) as well as workforce (limited workforce, challenges with accessing training or consultation).
- More research on how to systematically address program fidelity, training updates, quality assurance.
- Care transitions programs like Coleman are based on having access to a primary care provider. Need more research on ways to serve individuals who do not have a primary care provider and/or are socially isolated.

Workforce training

- Workforce development and training – effective training for aging and direct care workers that increases knowledge and caregiving skills, and decreases care providers frustration and burnout.
- Interest in national training guidelines and certification for direct care workers and healthcare providers; example of certification for diabetes educators – would like something similar for dementia care, that set standards and also allowed for the possibility of reimbursement.

Screening/diagnosis

- More research – and/or more clear guidelines – on appropriate screening and diagnosis. Concern about increase in use of screening tools like SLUMS or MOCA by individuals (case managers, RNs, social workers) that may be leading to incorrect diagnoses of Alzheimer's.

Cost Savings, Funding, and Sustainability

- Need more ROI studies of evidence-based programs and services, with particular interest in ROI of providing respite.

- Research that shows the impact that programs and services have on public benefits (Medicaid/state-funded programs) – research that can demonstrate any reducing of costs, delaying the need for higher levels of care, decreasing family caregiver burnout.
- More research on how to embed programs in existing systems (healthcare, aging services, housing, etc) to ensure sustainability.
- Why are evidence-based interventions not being taken to scale. Example of 4 RCTs on dementia care management – and REACH program – which have demonstrated outcomes, but are still not being adopted and widely used. Need work (eg research into why research is not enough to make these programs core services in health and aging systems?) to figure out why existing well-researched programs are not being taken to scale

Ways to share save-the-date and Summit info:

- Those on today’s call can send out to their networks, including RCI and Florida networks
- HRSA grantees (GECs)
- GSA
- Alzheimer’s Association
- Southern Gerontological Society
- University medical schools
- AARP – and specifically the current AARP public policy learning collaborative group (?)
- MLTSS Association
- CDC Prevention Resource Centers

Who to share resulting Summit findings/recommendations with:

- Same list as above
- Private funders – eg Grantmakers in Aging – as they may be able to focus future funding on identified research needs