



Service Provider Recommendations II

Stakeholder Group Paper

September 2017

Prepared by:
Provider 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, Services and Supports for Persons with Dementia and Their Caregivers

NIH Campus, Natcher Building #45 | 45 Center Drive | Bethesda, Maryland

October 16-17, 2017

PROVIDER STAKEHOLDER GROUP RECOMMENDATIONS - II

NIH Research Summit Provider Stakeholder Group Members

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Jennifer Carson	University of Nevada, Reno	Reno, NV
Molly Carpenter	Home Instead Senior Care	Omaha, NE
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Vanessa Emm	National Assoc. of Activity Prof.	Eau Claire, WI
Jonathan Evans	Amer. Medical Directors Assoc.	Columbia, MD
Maribeth Gallagher/Amy McLean	Hospice of the Valley	Scottsdale, AZ
Molly Rees Gavin	Connecticut Community Care	Bristol, CT
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Dear NIH Summit Steering Committee,

We appreciate the opportunity to provide input into the upcoming Summit. Please find our concluding comments that accompany our initial Recommendations submitted on May 17, 2017.

NIH Provider Stakeholder Group Moonshot Goal

By 2025, there is wide spread use of evidence-based, person-centered care to maximize ability and quality of life for all people living with dementia.

To meet this goal, the following steps must be accomplished:

1. Determine how best to measure quality of care and quality of life for people living with dementia.
2. Identify existing valid and reliable research tools that measure quality of care and quality of life for people living with dementia.
3. Determine what quality of care and quality of life tools have been used and validated in multiple settings among diverse people across the disease progression.
4. Establish measures and outcomes that are appropriate for use across the continuum of long term services and supports that balance safety and autonomy for persons living with dementia.
5. Validate that measures and outcomes are sustainable for providers to institute, are scalable and financially feasible.
6. Empower paid and unpaid care partners with valid, evidence-based quality of care and quality of life programs, practices and tools.
7. Ensure quality of care and quality of life measures, outcomes and tools are available, aligned and interoperable across the continuum of long-term services and supports including palliative/end of life care.

The Provider Stakeholder Group's vision is that the major goal and outcome of the Summit is for people to live well with dementia.

Respectfully submitted,

NIH Summit Provider Stakeholder Group