

Stakeholder Perspectives on Research Outcomes That Matter

Sarah Lenz Lock JD
AARP



#DementiaCareSummit

Perspectives of the Six Summit Stakeholder Groups

- **Persons Living With Dementia**
 - **Family Caregivers**
 - **Service Providers**
 - **States**
 - **Workforce**
 - **Payers**

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Persons Living With Dementia : Research Outcomes that Matter

- Person-centered assessment & care planning addressing individual preferences and quality of life
- Coordinated, culturally competent care after a diagnosis
- Effective treatment of neuropsychiatric symptoms
- Reduced financial burden on persons with dementia and family caregivers
- Reduced stigma, including use of better terms and language

Family Caregivers: Research Outcomes that Matter

- Reduced financial impact of caring for someone with dementia
- Reduced family caregiver stress and burden
- Better informed health care professionals, attorneys, bankers and other advisors
- Better understanding of family caregiver depression and stress and the resources required for caregiving
- More assistance and guidance with legal and financial issues
- More targeted services based on caregiver needs at different points in the care partner's disease

Service Provider s: Research Outcomes that Matter

- Evidence-based person-centered care maximizing ability and quality of life for all people living with dementia.
- Better measures of quality of care and quality of life for persons with dementia that:
 - Can be used across multiple settings, in diverse populations, and across disease progression
 - Are interoperable across the continuum of long term services and supports
 - Balance safety and autonomy of the person with dementia
 - Are financially sustainable
- Valid, evidence-based quality of care and quality of life programs, practices, and tools to empower paid and unpaid care providers.

State Stakeholder Group: Research Outcomes that Matter

- Options for financing long term services and supports
- Results of translation research that puts programs into practice
- Effective training for home care workers about caregiver needs, health, and well-being
- Programs that result in more underserved and culturally diverse families accessing optimal, evidence-based care
- Options for paying care workers a living wage
- Effective primary care interventions that address both caregiver and patient education and support

Workforce: Research Outcomes that Matter

- Core competencies and domains to define and build a dementia capable workforce
- Recruitment and retention strategies to expand the workforce
- Technologies to provide high quality care
- Costs and benefits of educating and training a dementia capable workforce
- Effective training to improve coordination of care and care transitions to improve outcomes and reduce costs
- Effective dissemination and implementation to translate research into education and training that transforms care and practices.

Payers: Research Outcomes that Matter

- Evidence-based interventions that:
 - improve health & well-being of members
 - increase value by reducing inappropriate utilization
 - For family caregiver training
- Eviden. of effectiveness based on quality & outcome measures that:
 - focus not only on the dementia but also on avoidance or management of co-morbid diseases and conditions
 - take into account the type and stage of dementia and the availability of formal and informal supports
- Reduction of:
 - caregiver burden and stress
 - behavioral symptoms
 - polypharmacy, chemical restraints, and falls
- Evidence about:
 - advance care planning and palliative care approaches
 - effective training for physicians and other providers to identify and diagnose dementia

Similarities and Differences in Perspectives Across Stakeholder Groups

- Similarities – all recognize that
 - Quality of care/life can be improved through evidence & training to deliver person-centered care
 - Adapt to the continuum of the disease from mild, moderate to severe over time
 - Financial sustainability and affordable options
 - Reducing caregiver burden central to 5 out of 6 groups
- Differences – unique to specific stakeholder groups
 - Caregivers: more sensitive to need for community support
 - Payers: recognize quality measures & outcomes need to evaluate impact of dementia on co-morbid conditions
 - Persons living with dementia: reduce stigma & recognizing individual preferences

Implications for Research Funders

- People living with dementia say reducing stigma is a priority so research into how to de-stigmatize the condition should also be a priority.
- Critical to address living well with dementia across the continuum of the disease.
- Urgent need for more effective training for paid and family caregivers.
- Financial Aspects such as value/cost effectiveness/sustainability should be evaluated.