Service Provider Recommendations

Stakeholder Group Paper

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Prepared by:
Provider Stakeholder Workgroup

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

NIH Research Summit
Provider Stakeholder Group Members

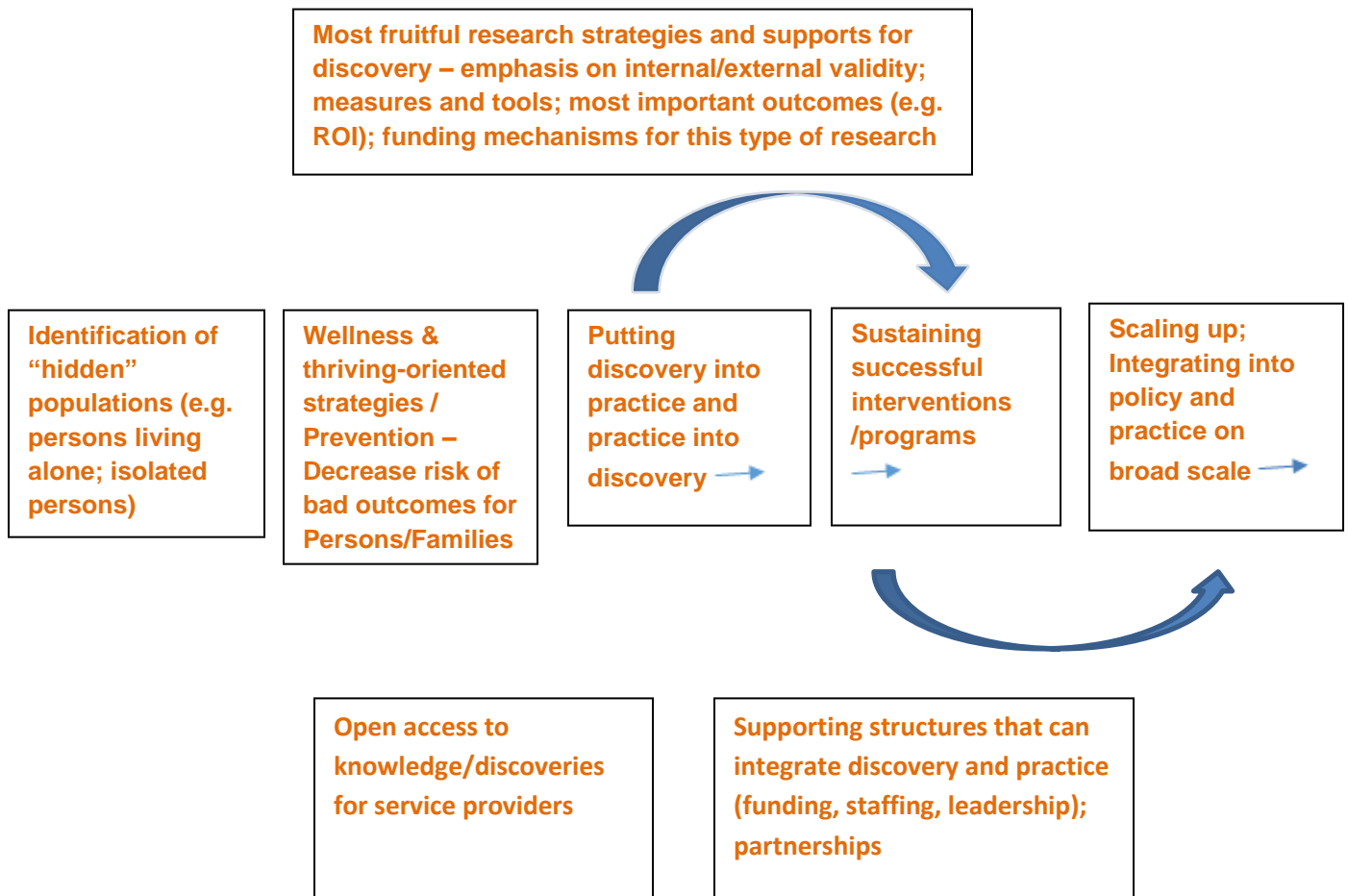|		
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PROVIDER STAKEHOLDER GROUP

Recommended Research Questions

There are several broad categories that emerged from the Provider Stakeholder conversations:

➢ Fostering Partnerships
➢ Provider Return on Investment (ROI)
➢ Turning Successful Practice-Based Interventions into Evidence-Based Interventions and Turning Evidence-Based Interventions into Feasible Practices
➢ Scaling Up Successful Interventions and Sustainability

Graphic to Assist in the Overall Themes Presented

Most fruitful research strategies and supports for discovery – emphasis on internal/external validity; measures and tools; most important outcomes (e.g. ROI); funding mechanisms for this type of research

Identification of "hidden" populations (e.g. persons living alone; isolated persons)	**Wellness & thriving-oriented strategies / Prevention – Decrease risk of bad outcomes for Persons/Families**	**Putting discovery into practice and practice into discovery →**	**Sustaining successful interventions /programs →**	**Scaling up; Integrating into policy and practice on broad scale →**

Open access to knowledge/discoveries for service providers

Supporting structures that can integrate discovery and practice (funding, staffing, leadership); partnerships

Research Theme: Person Centered Practices

1. How can providers proactively support well-being for persons living with dementia, family and professional caregivers (thereby greatly diminishing the need for reactive pharmacological and/or nonpharmacological interventions)? What are some of the existing best practices associated with various positive outcomes such as wellbeing, thriving and positive person living with dementia-caregiver dyad outcomes [as opposed to research focused on risk reduction, disability etc.]?

2. There is a need to discuss the bent towards the biomedical approach in research. Much of the best practices that providers "know" positively impacts the health and well-being of persons living with dementia and their caregivers is not solely biomedical but rather comes from good person-centered care ---and many are not validated by research.

3. There needs to be more research that validates and helps demonstrate the ROI of the "gold standard" practices of person-centered care. There are many documents that provide a good roadmap for those practices; e.g.

   a. http://www.theceal.org/images/reports/004Person-Centered-Care-Domains-of-Practice.pdf
   b. http://daanow.org/dementia-action-alliance/white-paper/
   c. https://acl.gov/NewsRoom/blog/2014/2014_07_09.aspx
   d. https://www.hhs.gov/ash/about-ash/multiple-chronic-conditions/education-and-training/curriculum/module-1-person-and-family-centered-care/index.html

Research Theme: Evidence-Based Practices

1. How can providers partner to share knowledge and provide more evidence-based research to back up the successful practices currently being used in the field that have little or no evidence to back them up.

2. What are the barriers to the implementation of evidence-based and/or best practices for dementia care approaches across service settings (e.g., personal home, nursing home, group home, assisted living)?

3. How can providers choose most effectively between evidence-based interventions to determine what services and supports to offer?

Research Theme: Care Staffing and Caregiver Training and Supports

1. What are strategies for staffing and sustaining delivery of evidence based interventions for paid and unpaid caregivers?

2. What is the effect of on-going/consistent dementia care staff training and support within long-term care facilities on staff job performance and burn-out and resident behavioral symptoms, quality of life, and activity engagement?

3. What are the changing needs of families/unpaid caregivers on caring for a person with dementia at home across stages of dementia? Demographic characteristics?

4. What is the effect of dementia care intervention targeting unpaid caregivers and people living with dementia receiving palliative care services on activity engagement, quality of life, caregiver burden?

Research Theme: Services and Supports

1. What are the beneficial outcomes from dementia-related training for first responders such as police officers, EMTs, firefighters, etc. for a person living with dementia as well as the first responders and the community?

2. What specific home and community-based services (HCBS) has demonstrated success in supporting persons with dementia and their caregivers? Are they cost effective for the individual, and for public programs? What enhancements to public programs might increase the spread of HCBS to this population?

3. What are the unique support, service, and intervention needs for persons with young-onset dementia?

4. How can medical and health homes incorporate best practices for dementia care?

Research Theme: Impact of Sensory Loss

1. Does overall sensory loss (hearing, vision, gait, etc.) and dementia contribute to the progression of dementia?

2. How can technology assist to avert or delay sensory loss?

Research Theme: Impact of Interventions Relating to External Environment

1. What is the effect of environmental characteristics (e.g. physical structure, noise, lighting, path of travel, décor, odor) within long-term care facilities (e.g. assisted living, nursing homes) on behavioral symptoms.

2. How can activity engagement in residents with dementia impact behavioral symptoms?

3. Propose an examination of the use of multi-modal complimentary alternative medicine (CAM) intervention programs e.g. healing touch, aromatherapy, light therapy and music intervention program.

Session II: Research on Supportive Approaches for Family and Other Caregivers

1. The barriers and rights of long-distance caregivers across state lines.

2. How is care impacted by illiteracy and the inability to speak English as well as an understanding of how language becomes complicated with dementia?

3. The need to address ambiguous loss (the feeling that your loved one is physically present but not the same person or no longer mentally with you) and caregiver stress. Banner Alzheimer's Institute's recently completed pilot study; Steps to H.O.P.E. (health, optimism, purpose, endurance) addressed the effects of both with positive outcomes.

4. How can technologies be combined with best practice interventions for caregivers?

Session III: Involving Persons with Dementia and Family and Other Caregivers as Active Members of the Research Team to Identify Research Topics and Meaningful Outcomes

1. Practice-based evidence as well as evidence-based practice; how to bolster both and work in partnership with those living the experience to generate research and knowledge.

2. Care settings that are not regulated by the government that use specialized approaches to care; e.g. assisted living facilities with specialized dementia care units.

3. There are operational clinical settings doing research in their own settings where the challenge is more practical/functional than funding. Results of that research in real-life settings often have confounds (other factors than the intervention being studied which may have influenced the outcome which make causal connections difficult to conclude), and consequently the results of that research don't get published.

4. Do specialized training programs for personal care assistants and other paid caregivers improve outcomes for persons/families/unpaid caregivers with dementia?

Session IV: Research on Care Coordination and Care Management for Persons with Dementia and Family Caregivers

Research Theme: Caregivers

To design and provide for an efficient and useful array of dementia caregiving support services, there is a need for functional information about caregivers who are providing primary supports to persons with dementia or serving as their primary advocates, and the types of caregiving situations and environments that are most viable. Studies should be undertaken in the following areas:

1. Identify patterns of caregiving and quantify the numbers of persons engaged in primary caregiver roles, enumerating (or estimating) their locations, specific supportive care needs, capacities for functional caregiving, and potential caregiving durations.

2. Examine that range of expenses incurred by persons engaged in primary caregiver roles, supplemental financial supports that can extend caregiving, how funds are derived, and secondary costs to communities to have in place caregiver supports and other services that address community dementia supports in any form.

3. Examine comparative models for 'dementia capable communities' with respect to process, outcomes, costs, and sustainable resources.

4. Compare predictive measures than can quantify risk of caregiving situations, housing situations that support continued at-home care, and the characteristics of secondary caregivers who can help sustain caregiving situations.

5. Determine cost-effective alternative community dementia care situations and environments, through to advanced dementia, that can enable continued in-community living and enable contacts with family and other persons, and which can preclude institutional admission.

6. Learn how to adapt existing caregiver interventions to better meet the needs of rural caregivers.

7. Determine how to engage more students (social work, PT, OT, nursing) to be interested in caregiver-related efforts, and maximize community partnerships.

8. Determine how to translate caregiver research into services and supports?

Research Theme: Persons Living Alone with Dementia

We need better demographic studies to determine the prevalence and characteristics of people with dementia living alone in the community.

1. Better demographic studies to determine the prevalence and characteristics of people in this group. Current studies vary widely. Informants need to include Adult Protective Services, fire, police and town officials, fuel delivery companies, postal services and hospital emergency departments, Area Agencies on Aging.

2. What strategies are most effective in identifying people living alone in the community with early stages of dementia?

3. Many of these people have become loners. What factors lead to a person having few or no reliable and willing others in their lives?

4. What are the determinants of persons with dementia living in the community becoming disconnected with clinical, community-based and other social supports?

5. How can we advance a connection to home and community-based and social services that evolves as the disease progresses?

6. What are the costs versus cost savings of complex care management intervention for PWD living alone? Some experiences show that they may use more medical services (many haven't been to a doctor for years) but that intervening in a comprehensive, collaborative way saves the costs of their repeat cycling of the person through law enforcement/rescue, community providers and APS.

7. What are the costs/benefits of intensive dementia care management in late stages?

8. Are PWD living alone more socially isolated and lonely than older adults living alone without cognitive impairment?

9. Are PWD more frequent and more generous donors to charitable organizations than older adults living alone without cognitive impairment? Are increasingly frequent donations (the more you give the more often you get solicited) positively correlated with cognitive decline?

10. What tools/guidelines are needed to balance autonomy and risk acceptance with safety and protection from abuse and self-neglect? How do we measure the outcomes?

11. What do communities need in order to provide adequate supports for residents with dementia?

12. What are the validated tools for determining and weighing risk?

13. Can the Allen Cognitive Level assessment of functioning determine risk, ability to live alone, and strategies for supporting the person's best ability to function?

14. What are the validated measures for determining a client's progression along a "Crisis to Thriving" continuum?

Research Theme: Funding for Research

1. What funding opportunities can be developed beyond grants?

2. What are effective strategies to establish a price structure for realistically seeking funding from private and public entities for evidence-based program delivery?

3. How can providers establish a cost/benefit basis to attract funding sources?

4. How can providers measure program benefits in terms of cost, in addition to measuring impact on caregivers and care recipients?

Research Theme: Exploration of Palliative/Hospice Dementia Care, Advance Directives, and Estate Planning.

1. Palliative / hospice dementia care:

    Studies indicate hospice services for people with advanced dementia *and* their families/caregivers have numerous positive benefits (e.g., decreased hospitalizations, more effective management of distressing symptoms, greater satisfaction).

    a. How can we increase knowledge, access and referrals to hospice services so hospice is a standard treatment option and viable choice in the array of services offered to every person with advanced dementia and their families who choose to focus on comfort?

    b. Compare and contrast various outcomes (e.g., comfort measures, avoidable ER visits and hospitalizations, polypharmacy, caregiver burden/satisfaction, private/public costs) for those who choose palliative care, with those who do not.

    c. How can we best implement and sustain practices that support well-being in the person with advanced dementia, family caregivers, paid caregivers and healthcare professionals across care settings?

    d. How do educational and support needs vary depending on the type of caregiver and setting including personal homes, group homes, hospitals, hospice and palliative care, assisted living facilities, and nursing homes?

e. The advanced stage of dementia can last for years, but the hospice benefit is offered only for the last 6 months of life. Now that we have evidence of the positive benefits palliative care offers patients and their care partners, why don't we offer this care to all who need it, including the person with dementia?

f. How can palliative care be advanced as a defined benefit in private insurance, Medicare, and Medicaid?

2. Advance Directives

While many people with dementia can direct and participate as the center of their person-centered plan of care, there is room for significant improvement in helping them complete their health care decisions, which may ultimately lighten the burden left on families and caregivers. For many, this is a complicated and emotional discussion.

a. How do we prepare professionals to skillfully provide compassionate and informed decision-making support for persons living with dementia and their caregivers in order to increase the completion of advance directives in this population?

b. What are the most effective methods to ensure widespread dissemination of the evidence-based outcomes associated with advance directives (CPR, hospitalizations, antibiotics, feeding tubes) as they pertain to people with advanced dementia, in order to maximize comfort and decrease health care utilization that does not align with a person's goals of care?

c. Pre-Hospice Palliative Care for Dementia Service to People in any Stage and Their Care Partners
    i. How can a 24/7 dementia-specific triage line capable of addressing medical and psychosocial concerns impact 911 calls and ER visits, as compared to a dementia caregiver's traditional Monday-Friday 8-5 options for medical and community-based support?
    ii. What are the specific skills and knowledge essential for triage staff to effectively respond to such calls?

Research Theme: Cross-Cutting Themes for Care Coordination

1. Is there a role for Doctor of Nursing Practice (DNP)-prepared nurse leaders and graduate nursing students in providing a free flow of communication between research, evidence-based practice and research inspired by practice-based wisdom?
2. What are the characteristics of a dementia-capable community, and how should we share best practices?

3. What are the best practices in nonpharmacological dementia care?

Session V: Challenges in Involving Persons with Dementia as Study Participants in Research on Care and Services

1. How do we engage the person with dementia and the caregiver to participate with researchers in setting the research agenda and answering questions that are important to them?

2. Can we develop and test more effective ways to gather data from persons with moderate or severe dementia and measure outcomes other than proxy measures (e.g. are there methods and techniques used in other populations or sciences that might inform research with persons with dementia)?

3. In addition to discussing the establishment of research partnerships to examine effective dementia care interventions, we should also consider the proper standards, expectations and dissemination strategies for that research. Research partnerships in practice-based settings, particularly long-term care settings (both community-based and institutional), are likely to face a number of challenges to standardization and control. Specifically, applying strict Evidence-Based Treatment (EBT) criteria requires specific methodological standards such as comparison of a single treatment condition to a control group, random assignment to treatment and control groups, blinded administration of outcome measures, replication of results in the literature, sample sizes typically over 30 participants, and strict adherence to treatment protocols. Achieving these research standards in an active clinical setting, and particularly in long-term care settings, is difficult, if not impossible. The day-to-day operations of any setting, but particularly in a nursing home, present a multitude of challenges to controlled studies, including the ever-changing demands of resident care, the multitude of staff involved in care, and the competing priorities within the care environment. All these factors make it difficult to ensure that a particular intervention is delivered in a standardized manner and that data is collected consistently and correctly. As a result, studies conducted in institutional settings can have a lack of internal controls and often fail to achieve the strict standards of EBT research.

   The issues above suggest that consideration of the proper standards and expectations of research in particular settings should be examined. For example, one might argue that intervention studies conducted in institutional settings should emphasize external validity over internal controls, rather than vice versa. Moreover, consistent with the focus of the National Institute of Mental Health's Dissemination and Implementation Research Program, research that investigates the adoption of efficacious interventions in various settings should perhaps become our goal versus the laborious process of establishing EBT as strictly defined.

Session VI: Research on Partnerships, Translation, Dissemination, Implementation, and Scaling Up of Effective Care, Services, and Supportive Approaches for Persons with Dementia and Family and Other Caregivers

Research Theme: Research Partnerships

1. How do we foster effective *research partnerships* between researchers, providers and persons living with dementia to enable participatory, practice-based and practice-led research (e.g., action research) to examine, improve and innovate dementia care and support practices (thereby bridging the gap between research and practice, while strengthening the relevance of research)?

2. What does the evidence say about the effectiveness of academic-practice partnerships as a vehicle for translating evidence into practice?

3. How do we foster partnerships between researchers and practitioners as a vehicle for translating evidence into practice? For example, a hurdle providers experience as non-academicians is access to research results. In many cases as providers are developing new programs, services, supports, and practices, they want to consult the latest research on a given topic. Access to those results is costly with some article reprints at over $100. Many provider organizations do not have budgets that support journal subscriptions or conference attendance. Transference of the evidence-base into practice can only come if we have access to the research results--perhaps there needs to be more proactive dissemination of their results to those of us who can transfer it into common practice?

Research Theme: Outcomes

1. What value do payers want or need to see that will help them adopt/incorporate successful practices (ROI, decreased readmissions, healthcare cost savings, self-direction, person-centered care, duty to help individuals, choice, access, control)?

2. There is a need for research that compares/contrasts the benefits of person-centered approaches while demonstrating healthcare provider return on investment (ROI). How do we show healthcare providers the connection between effective interventions and overall healthcare costs related to persons with dementia and the power they provide to keep healthcare costs down (reduced readmissions, missed doctor appointments, fewer ambulance rides, ER visits, etc.) and improve care quality? In light of overall healthcare costs and possible federal budget cuts, we need to demonstrate the predicted costs of persons with dementia and other comorbidities to private and public payers, what this means for overall costs, and how costs can be reduced with other interventions and services and supports.

Research Theme: Measuring Outcomes

1. What are the best tools, measures and methods to identify research outcomes; are there innovative methods used in other populations (e.g. persons with autism spectrum disorder, or intellectual disability or pediatric populations) that might be valuable if validated in persons with dementia and which might reduce reliance on proxy measures?

2. How does technology help us collect and track data?

Research Theme: Translation

Showcase examples of those who have translated an evidenced approach to the community base in a successful way involving growth and sustainability. What are their proven approaches and the research on scaling up?