



# Examining Models of Dementia Care

1

RTI International is a registered trademark and a trade name of Research Triangle Institute.

[www.rti.org](http://www.rti.org)

## Acknowledgement

- This study was funded by ASPE under contract number HHSP23320100021W1
- Rohini Khillan, MPH, was the Project Officer
- All views expressed in this presentation are those of the authors and do not necessarily represent the views of ASPE or RTI International

2

## Project Team

### **RTI International**

Joshua M. Wiener, PhD, Project Director

Elizabeth Gould, MSW

Sari Shuman, MPH, MSW

Ramandeep Kaur, PhD

Magdalena Ignaczak, BS

### **Independent Consultant**

Katie Maslow, MSW

3

## Introduction

- Nonpharmacological approaches and care practices have been shown to have positive effects for some people with Alzheimer's disease or other dementias.
- Although many organizations have guidelines on good dementia care, current systematic syntheses of those guidelines may be lacking.
- Little is known systematically about what services dementia programs provide across settings.
- Little is known about how programs address desirable care components.

4

## Project Activities

- Synthesize existing dementia care guidelines
- Develop catalog of dementia care programs
- Drawing from catalog of dementia care programs, conduct case studies of five programs to assess how they meet our dementia care guidelines
- Conduct cross-site analyses and draw implications for dementia care and future research

5

### Synthesize Existing Dementia Care Guidelines

- Identified 37 sets of dementia care guidelines, which focused on structure and process rather than outcomes
- Identified 16 (later revised to 14) key domains
- Synthesized guideline recommendations into both high-level and more specific recommendations
- Goal was standards that were profession-, setting- and dementia-stage free
- Care components reviewed by five experts in the field

6

## Dementia Care Components

- Detection of possible dementia
- Diagnosis
- Assessment and ongoing reassessment
- Care planning
- Medical management
- Information, education, and informed and supported decision-making
- Acknowledgment and emotional support for the person with dementia

7

## Dementia Care Components (cont.)

- Assistance for the person with dementia with daily functioning and activities
- Involvement, emotional support, and assistance for family caregiver(s)
- Prevention and mitigation of behavioral and psychological symptoms of dementia
- Safety for the person with dementia

8

## Dementia Care Components (cont.)

- Therapeutic environment, including modifications to the physical and social environment of the person with dementia
- Care transitions
- Referral and coordination of care and services that match the needs of the person with dementia and family caregiver(s) and collaboration among agencies and providers

9

## Identification of Models of Dementia Care

- Conducted environmental scan to:
  - Provide a catalog of interventions
  - Provide universe from which case studies could be selected
- Included variety of settings—nursing homes, residential care facilities, home and community-based services, primary care, hospice, and caregiver support programs
- Focus on evidence-based programs and interventions that have been translated to community settings
- Identified 55 interventions, mostly community-based settings that provided support for caregivers

10

## Case Studies

- How do “real-life” programs address the 14 care components?
- From pool of 55 interventions/programs, selected 5 programs for case studies
- Range of type of program

11

## Case Studies (cont.)

- BRI Care Consultation™ (Cleveland, Ohio)
- Comfort Matters™ (Phoenix, Arizona)
- Healthy Aging Brain Center (Indianapolis, Indiana)
- MIND at Home (Baltimore, Maryland)
- RCI REACH (Georgia)

12

## Case Study Findings

- None of the five programs had procedures to detect possible dementia in the general population.
- None of the five programs directly addressed all 14 components, but most of the programs addressed most of the components.
- Programs used three ways to address components: direct provision of the needed assistance; referral to another agency; and information, education, skills training, and encouragement to help family caregivers.

13

## Case Study Findings (cont.)

- All programs conducted assessment, reassessment, and care planning activities that facilitated the provision of individualized, person-centered care.
- Programs with medical staff were able to provide formal diagnosis of dementia. Other programs sometimes referred for diagnostic evaluations, but a formal diagnosis was not a prerequisite for participation in any programs.

14

## Conclusions

- Although there is no cure for Alzheimer's disease, there are a substantial number of evidence-based interventions that have some effect on outcomes such as caregiver burden and depression.
- Extremely large number of dementia care guidelines exist, but not quantitative measures.
- Development of dementia care components is a major advance and should be disseminated and endorsed by relevant organizations.

15

## Conclusions (cont.)

- With only five case studies, not possible to make definitive judgments; additional case studies would improve our understanding.
- We found:
  - Most programs address the vast majority of dementia care components, either directly or indirectly.
  - Most programs focused on caregivers rather than person with dementia; residential and medical programs most likely to have substantial interaction with person with dementia.

16

## Conclusions (cont.)

- Programs varied greatly in the degree to which they were involved in medical management.
- Several programs had invested a great deal of effort into developing a library of resources for people with dementia and caregivers; a federal initiative to do that might be appropriate.

17

## Contact Information

Elizabeth Gould, MSW  
RTI International  
230 W. Monroe St. Suite 2100  
Chicago, IL 60606  
[egould@rti.org](mailto:egould@rti.org)

18

## April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Monday, April 17, 2017, in Washington, DC. The Advisory Council spent the majority of the April meeting considering recommendations made by each of the three subcommittees for updates to the 2017 National Plan. Afternoon presentations included a presentation on results from a research project on dementia care components, planning progress towards a Care and Services Summit, and federal workgroup updates. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2017>.

Comments and questions, or alerts to broken links, should be sent to [napa@hhs.gov](mailto:napa@hhs.gov).

---

### General Information

<b>Agenda</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Announcement</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Meeting Summary</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Public Comments</b>	<a href="#">[HTML Version]</a>

### Handouts

<b>LTSS Subcommittee 2017 Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
---	--

### Presentation Slides

<b>2017 Research Subcommittee Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Alzheimer's and Related Dementias Research</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Care Subcommittee Report</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Clinical Services Subcommittee Federal Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Examining Models of Dementia Care</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>Long Term Services and Supports Subcommittee Recommendations</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

<b>Long-Term Services and Supports Committee Update</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>
<b>National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers Progress to Date</b>	<a href="#">[HTML Version]</a> <a href="#">[PDF Version]</a>

## Videos

<b>Welcome, LTSS, and Clinical Care Recommendations</b>	<a href="#">[Video]</a>
<b>Research Recommendations, Council Discussion/Vote, Overview of Legislative Processes</b>	<a href="#">[Video]</a>
<b>Public Comments and Examining Models of Dementia Care</b>	<a href="#">[Video]</a>
<b>Care Summit Update and Federal Workgroup Updates</b>	<a href="#">[Video]</a>

---

Last Updated: 06/27/2018