



**U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy**

# **EXAMINING MODELS OF DEMENTIA CARE:**

## **FINAL REPORT**

**September 2016**

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This report was prepared under contract #HHSP23320100021WI between HHS's ASPE/DALTCP and the Research Triangle Institute. For additional information about this subject, you can visit the DALTCP home page at <https://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp> or contact the ASPE Project Officer, Rohini Khillan, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: [Rohini.Khillan@hhs.gov](mailto:Rohini.Khillan@hhs.gov).

# **EXAMINING MODELS OF DEMENTIA CARE: Final Report**

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# TABLE OF CONTENTS

<b>ACKNOWLEDGMENT</b> .....	iii
<b>ACRONYMS</b> .....	iv
<b>EXECUTIVE SUMMARY</b> .....	vii
<b>1. INTRODUCTION</b> .....	1
1.1. Introduction References.....	2
<b>2. DEMENTIA CARE COMPONENTS</b> .....	4
2.1. Methodology for Developing Dementia Care Components .....	4
2.2. Final Care Components.....	6
2.3. Care Components References .....	13
<b>3. CASE STUDIES/SITE VISITS</b> .....	18
3.1. BRI Care Consultation™ .....	28
3.2. Comfort Matters™ .....	34
3.3. Healthy Aging Brain Center .....	39
3.4. MIND at Home.....	46
3.5. RCI REACH.....	52
3.6. Case Studies References .....	57
<b>4. CONCLUSION</b> .....	59
4.1. Possible Next Steps .....	65
<b>APPENDICES</b>	
APPENDIX A-1. Guideline Standards, by Category .....	A-1
APPENDIX A-2. Components of Dementia Care, by Guideline.....	A-45
APPENDIX B. Selected Dementia Models.....	A-50
APPENDIX C. Sample Dementia Care Program Site Visit Discussion Guide.....	A-68

## LIST OF TABLES

TABLE ES-1. Dementia Care Framework Components .....	vi
TABLE 2-1. Dementia Care Framework Components .....	7
TABLE 2-2. Detailed Dementia Care Framework Components .....	8
TABLE 3-1. Description of Dementia Care Programs Visited .....	20
TABLE 3-2. Summary of How the Dementia Care Models Address the Care Components .....	23
TABLE 3-3. Action Steps Examples .....	30
TABLE 3-4. Key Concepts of Comfort Matters .....	34

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## ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ABC	Antecedent-Behavior-Consequence
ACCESS	Alzheimer's Disease Coordinated Care for San Diego Seniors
ACT	Advanced Caregiver Training
ADC program	Alzheimer's and Dementia Care program
ADL	Activity of Daily Living
AICT	Advanced Illness Care Team
ANSWERS	Acquiring New Skills While Enhancing Remaining Strengths
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
BPSD	Behavioural and Psychological Symptoms of Dementia
BRIA	Benjamin Rose Institute on Aging
CAM therapy	Complementary Alternative Medicine therapy
CCIS	Care Consultation Information System
CD	Compact Disc
CDSS	Clinical Decision Support System
CMS	HHS Centers for Medicare and Medicaid Services
COPE	Care of Persons with Dementia in their Environment
CSB	Caregiver Skill Building
CT	Computed Tomography
DBT	Dialectical Behavior Therapy
DSM-IV-R	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Revision
DVD	Digital Versatile Disc
ECHO-AGE	Extension for Community Outcomes-AGE
EEG	Electroencephalogram
EFNS	European Federation of Neurological Sciences
ENS	European Neurological Society
ERCC	Enhanced Respite Control Condition
ESML	Early-Stage Memory Loss
FAST	Functional Assessment Staging Test
FITT-C	Family Intervention: Telephone Tracking-Caregiver
HABC	Healthy Aging Brain Care
HEDIS	Healthcare Effectiveness Data and Information Set

HHS HIV	U.S. Department of Health and Human Services Human Immunodeficiency Virus
IADL INTERACT	Instrumental Activity of Daily Living Interventions to Reduce Acute Care Transfers
MDS MMSE MRI	Minimum Data Set Mini-Mental State Examination Magnetic Resonance Imaging
NCCA NIA NICE-SCIE	National Center for Creative Aging HHS National Institute on Aging National Institute for Health and Clinical Excellence-Social Care Institute for Excellence
NITE-AD NYUCI	Nighttime Insomnia Treatment and Education for Alzheimer's Disease New York University Caregiver Intervention
PACSLAC	Pain Assessment Checklist for Seniors with Limited Ability to Communicate
PAINAD scale PCP PEACE PHQ PLST PQRS Project CARE PT	Pain Assessment in Advanced Dementia scale Primary Care Provider Palliative Excellence in Alzheimer Care Efforts Patient Health Questionnaire Progressively Lowered Stress Threshold Physician Quality Reporting System Caregiver Alternatives to Running on Empty Project Physical Therapy
RCI RDAD REACH RN	Rosalynn Carter Institute for Caregiving Reducing Disability in Alzheimer's Disease Resources for Enhancing Alzheimer's Caregiver Health Registered Nurse
SSRI STAR-C	Selective Serotonin Reuptake Inhibitor Staff Training in Assisted-living Residences-Caregivers
TAP TCARE TCM TEP	Tailored Activity Program Tailored Caregiver Assessment and Referral Transitional Care Model Telehealth Education Program



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## EXECUTIVE SUMMARY

A growing number of programs to help persons with dementia and their family caregivers are being developed, tested, and implemented in the United States. To learn more about whether and how models of dementia care meet practice standards, 14 components of comprehensive dementia care were identified and site visits conducted to a small sample of programs to assess how they are implemented.

The dementia care components were identified through a detailed analysis of 37 existing clinical guidelines and practice recommendation documents. The 14 identified components differ from most of the clinical guidelines and practice recommendation documents in that they encompass aspects of care for people in all stages of dementia and their families, in multiple care settings, from home to nursing home and medical care settings, and provided by a wide array of medical, social, and allied health care professionals, paraprofessionals, and direct care workers. The project postulated that most of the activities required to address the components could be performed by various types of trained professional, paraprofessional, and direct care workers. An exception to this assumption is medical management activities that can only be performed by a physician or other medical care provider who is authorized to perform them under state law and regulations for particular public programs and settings (e.g., prescribing medications). From a perspective of possible quality or assessment measures, these components are structural or process measures; they are not outcome measures.

**Table ES-1** presents high-level principles of normative care derived from the review of the guidelines.

TABLE ES-1. Dementia Care Framework Components	
1. Detection of Possible Dementia	Examine for cognitive impairment when there is a decline from previous function in daily activities, occupational ability, or social engagement.
2. Diagnosis	Obtain a comprehensive evaluation and diagnosis from a qualified provider when cognitive impairment is suspected.
3. Assessment and Ongoing Reassessment	Assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, and safety. Reassess regularly and when there is a significant change in condition.
4. Care Planning	Design a care plan that will meet care goals, satisfy the person's needs, and maximize independence.
5. Medical Management	Deliver timely, individualized medical care to the person with dementia, including prescribing medication and managing comorbid medical conditions in the context of the person's dementia.

<b>TABLE ES-1 (continued)</b>	
6. Information, Education, and Informed and Supported Decision Making	Provide information and education about dementia to support informed decision making including end-of-life decisions.
7. Acknowledgement and Emotional Support for the Person with Dementia	Acknowledge and support the person with dementia. Allow the person's values and preferences to guide all aspects of the care. Balance family involvement with individual autonomy and choice.
8. Assistance for the Person with Dementia with Daily Functioning and Activities	Ensure that persons with dementia have sufficient assistance to perform essential health-related and personal care activities and to participate in activities that reflect their preferences and remaining strengths; help to maintain cognitive, physical, and social functioning for as long as possible; and support quality of life. Provide help as needed with medication management and pain control.
9. Involvement, Emotional Support, and Assistance for Family Caregiver(s)	Involve caregiver in evaluation, decision making, and care planning and encourage regular contact with providers. Provide culturally sensitive emotional support and assistance for the family caregiver(s).
10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	Identify the causes of behavioral and psychological symptoms, and use nonpharmacological approaches first to address those causes. Avoid use of antipsychotics and other medications unless the symptoms are severe, create safety risks for the person or others, and have not responded to other approaches. Avoid physical restraints except in emergencies.
11. Safety for the Person with Dementia	Ensure safety for the person with dementia. Counsel the person and family as appropriate about risks associated with wandering, driving, and emergency preparedness. Monitor for evidence of abuse and neglect.
12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	Create a comfortable environment, including physical and social aspects that feel familiar and predictable to the person with dementia and support functioning, a sustained sense of self, mobility, independence, and quality of life.
13. Care Transitions	Ensure appropriate and effective transitions across providers and care settings.
14. 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	Facilitate connections of persons with dementia and their family caregivers to individualized, culturally and linguistically appropriate care and services, including medical, other health-related, residential, and home and community-based services. When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care.

Five dementia care programs were selected for site visits from more than 50 possible programs. With only five programs, it is not possible to represent the full array of existing programs to help persons with dementia and their family caregivers. Nevertheless, the five programs were chosen to represent various program settings and ways of implementing the 14 identified dementia care components.

One of the five programs was based in a medical clinic, one was based in a residential care setting, and three were based in community agencies. The five programs were:

- BRI Care Consultation™ in Cleveland, Ohio;

- Comfort Matters™ in Phoenix, Arizona;
- Healthy Aging Brain Center in Indianapolis, Indiana;
- MIND at Home in Baltimore, Maryland; and
- RCI REACH, in the Rosalynn Carter Institute for Caregiving in Americus, Georgia.

In-person site visits were conducted for four of the programs, and telephone interviews were conducted for one program because of the travel distances involved. The purpose of the site visits was to examine how the programs were addressing each of the care components. Structured discussion guides were prepared for each site visit.

Findings from the site visits include the following:

- None of the five programs had procedures in place to detect possible dementia in general populations.
- None of the five programs directly addressed all 14 components, but most of the programs addressed most of the components. Program administrators indicated that some of the components are out of the scope of their program.
- The five programs used at least three ways to address the components: direct provision of the needed assistance; referral to another agency or individual that could provide the needed assistance; and information, education, skills training, and encouragement to help family caregivers provide the needed assistance.
- All five programs conducted assessment, reassessment, and care planning activities that facilitated the provision of individualized, person-centered care.
- There are similarities and differences in exactly how the programs interacted with persons with dementia and family caregivers.
- Programs with physicians or other primary care providers on staff were able to provide diagnostic evaluations leading to a formal diagnosis of dementia. Other programs were able to refer for diagnostic evaluations, but a formal diagnosis was not a prerequisite for participation in any of the programs.
- All five programs provided assessment and ongoing reassessment, but the assessment instruments and procedures they used vary.
- Some of the programs provided medical management, and others did not.
- All five programs had assembled information on many relevant topics to educate persons with dementia and family caregivers and support informed decision making.

- The four programs that were working with community-living people with dementia and their family caregivers interacted less often and less directly with persons with dementia than with family caregivers.
- At least two of the five programs have been disseminated to other sites across the country.

As the number of people with dementia grows larger over time, it will be increasingly important to better understand what different models of care provide and how effective they are in meeting the needs of persons with dementia and their caregivers.