

Selected Resources Developed by the National Alzheimer's and Dementia Resource Center



Selected Resources Developed by the National Alzheimer's and Dementia Resource Center

June 2020

Prepared for

Erin Long, MSW
Administration on Aging
Administration for Community Living
Mary Switzer Building 330 C Street, SW
Washington, DC 20201

Prepared by

Madeline J. Murray, BA
Sari B. Shuman, MPH, MSW
RTI International
3040 Cornwallis Road
Research Triangle Park, NC 27709

Contract Number HHSP233201600021I

Table of Contents

Section	Page
Introduction	1
Advance Planning.....	1
Article Resource List on Dementia Care and Services.....	1
Caregivers and Behavioral Symptoms.....	1
Dementia Capability.....	2
Education Resources for People Living with Dementia and Caregivers.....	2
Evidence-Based and Evidence-Informed Interventions.....	2
Grant Project Profiles	3
Alzheimer’s Disease Initiative-Specialized Supportive Services (ADI-SSS).....	3
Alzheimer’s Disease Program Initiative (ADPI)	3
Alzheimer’s Disease Supportive Services Program (ADSSP).....	3
Intellectual and Developmental Disabilities (IDD) and Dementia	4
People Living Alone with Dementia	4
Planning Resources for Dementia Projects	5
Screening, Identification, Referral, and Care Planning	6
Special Topics	6
Training Resources for Providers and Volunteers	6

Introduction

Over time, the National Alzheimer's and Dementia Resource Center (NADRC) has produced a range of resources on topics related to offering Alzheimer's disease and dementia supportive services. This document highlights selected resources developed by the NADRC. The intention of this document is to share these resources with Administration for Community Living/Administration on Aging (AoA) grantees and others working in the area of dementia to assist in efforts to deliver dementia care services and supports and to develop dementia-capable systems.

Grantees and others are encouraged to use these resources freely or as a starting point in program development and delivery of dementia care services and supports. As the NADRC continues to develop resources, they will be added to the NADRC website and this document will be updated accordingly. Each item listed below includes a description and link to the specific page on the NADRC website where the full resource is available.

Advance Planning

- [Living with Dementia: Advance Planning Guides for Persons with Dementia and Caregivers \(2017\)](#): This resource includes four advance planning guides for people living with dementia and their caregivers. The four guides are on topics including health care planning, planning for care, financial planning, and decision making. Each of the guides will help people living with dementia and their caregivers plan for current and future needs.

Article Resource List on Dementia Care and Services

- [Resource List of Articles on Dementia Care and Services](#): The NADRC regularly prepares a list of recently published articles covering a range of subjects of interest to grantees and partners. The list does not represent a comprehensive examination of the recent literature in any one subject or topic. Links to the publishers' websites are included if an article is available for purchase or for free download.

Caregivers and Behavioral Symptoms

- [Training Family Caregivers on Skills for Behavioral Symptoms](#): This paper describes a variety of approaches designed to support caregivers of people living with dementia to effectively address behavioral and psychological symptoms of dementia (BPSD). Effective psychosocial interventions that improve self-efficacy and empower the caregiver to address BPSD are discussed within the document.

With a goal of maximizing the quality of life for both people living with dementia and their caregivers, the interventions discussed may be designed for use by formal care staff or by informal or family caregivers in the home environment.

Dementia Capability

- [Dementia Capability Assessment Tool](#): This assessment tool is designed to measure the dementia capability of the long-term services and supports in various organizations. The information resulting from this assessment will assist in measuring changes in dementia capability over time.
- [Dementia Capable States and Communities: Lessons Learned from Administration on Aging Grantees](#): This paper provides a background on dementia-capable states and communities by presenting the need for dementia capability and outlining its evolution. Snapshots of dementia-capable programs across the United States resulting from AoA dementia grants are included. The paper also outlines the components of a model dementia-capable system, guides readers through the development of dementia-capable systems, and provides examples of dementia-capable practices at both state and community levels.

Education Resources for People Living with Dementia and Caregivers

- [Education Resources for People Living with Dementia, Their Family Members and Other Caregivers](#): This resource includes links to webpages, message boards, blogs, and videos to assist people living with dementia and family caregivers to manage daily activities as they navigate changes in cognition and abilities. These resources are free of charge and come from a variety of sources, including government, academia, government-funded Alzheimer's disease centers, and nonprofit organizations dedicated to Alzheimer's disease and related disorders.

Evidence-Based and Evidence-Informed Interventions

- [Grantee-Implemented Evidence-Based and Evidence-Informed Dementia Interventions](#): This resource contains a list of evidence-based and evidence-informed interventions that meet AoA criteria and have been implemented by AoA grantees beginning in 2007. The list includes information related to each intervention such as a brief description, the targeted population, peer-reviewed publications of the original studies that examine the model's effectiveness, and publications from AoA grant projects.

- [Translating Evidence-Based Dementia Interventions to the Community: Experience of the Administration on Aging's ADSSP Grantees](#): In 2008, AoA shifted the focus of the Alzheimer's Disease Supportive Services Program (ADSSP)—AoA's program that provided grants to states to improve dementia services—to support projects that translate evidence-based, nonpharmacological interventions from research to practice in the community. This report analyzes the experience of 16 ADSSP state grantees and their community partners to understand issues they confronted and strategies they used to address them while implementing various evidence-based dementia interventions.

Grant Project Profiles

Grant project profiles are downloadable documents that contain a summary of each grant project and planned activities, grantee contact information, and a list of partner organizations. Planned activities for each grant project are aligned with the specific program requirements defined by the AoA.

Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS)

- [2015 ADI-SSS Grant Project Profiles](#)
- [2016 ADI-SSS Grant Project Profiles](#)
- [2017 ADI-SSS Grant Project Profiles](#)

Alzheimer's Disease Program Initiative (ADPI)

- [2018 ADPI Grant Project Profiles](#)
- [2019 ADPI Grant Project Profiles \(June\)](#)
- [2019 ADPI Grant Project Profiles \(September\)](#)

Alzheimer's Disease Supportive Services Program (ADSSP)

- [2013 ADSSP Grant Project Profiles](#)
- [2014 ADSSP Grant Project Profiles](#)
- [2015 ADSSP Grant Project Profiles](#)
- [2016 ADSSP Grant Project Profiles](#)
- [2017 ADSSP Grant Project Profiles](#)

Intellectual and Developmental Disabilities (IDD) and Dementia

- [IDD and Dementia](#): This white paper provides a broad overview of services and support systems for people living with IDD affected by dementia and their caregivers, examples of cross-network initiatives, and resources for improving dementia care across agencies and organizations that serve this population. The current state of services and support systems for people living with IDD and dementia is presented and considerations for future development of community-based services for people living with IDD and dementia are discussed.
- [Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals](#): The guide provides background information and strategies for professionals working with people living with IDD and dementia. The guide is organized into 12 sections that address different aspects of identifying and providing services to people living with IDD and dementia or who are at risk of developing dementia. Tools are included for professionals to share with family caregivers or other caregivers who work with people living with IDD and dementia.

People Living Alone with Dementia

- [Handbook for Helping People Living Alone with Dementia Who Have No Known Support](#): This handbook provides guidance to professionals and tools for helping people living alone with dementia who do not have formal supports, including people living with dementia who have a caregiver who cannot provide support. The handbook discusses strategies for identifying people who are living alone without support, assessing risk, building trust, and options for helping the person maintain their independence.
- [Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone](#): This report provides information on the known prevalence of people living with dementia who live alone in the community and summarizes strategies for identifying and providing services to this population. The report highlights indications that a person with dementia living alone is not able to adequately manage his or her personal care needs and daily activities and describes supportive practices to assist people living alone with dementia.
- [Providing Services to Individuals with Dementia Who Live Alone: A Guide of Practical Strategies](#): This guide provides practical strategies to address certain challenges service providers encounter when working with people with

dementia who live alone. The content comes from a literature review and interviews with subject matter experts. The literature review was used to determine the state of the science and current practices used with people with dementia who live alone. The subject matter expert interviews informed the strategies addressed in this guide.

Planning Resources for Dementia Projects

- [Business Planning for Dementia Programs: Toolkit for Nonprofit and Government Agencies](#): Using a basic business plan template as an organizing framework, this toolkit provides a guide for writing the components of a business plan. Although the toolkit focuses on dementia programs, the questions posed consider larger issues, such as an assessment of internal organizational capabilities and external constraints in the marketplace. These factors influence choice of the business model, operational approach, financing, implementation success, and sustainability.
- [Evaluating Dementia Services and Supports: Instrument Resource List](#): This resource list was created to streamline the process of identifying and locating validated instruments for community-based dementia programs. The list includes 77 instruments and covers domains such as caregiver burden, depression, social support, and dementia knowledge. For each instrument, the list includes domain name, instrument and citation links, number of items, examples, instructions and information on scoring, and any special permissions. **Note:** Instruments that are not available elsewhere online are available here [on the NADRC website](#).
- [Measuring the Impact of Dementia Friendly Education and Training Sessions: A Toolkit](#): This toolkit was created by the AoA, a group of AoA grantees involved in dementia-friendly activities, and the NADRC. The brief tools included in the document can be used to measure the impact of dementia-friendly training and education efforts by evaluating knowledge, attitudes, and behavior or practice change outcomes. The toolkit also includes background on how the tools were developed; information about the use, scoring, and reporting of the tools; and an annotated version of the tools.
- [Writing an Effective Work Plan and Evaluation Plan](#): This webinar focuses on writing an effective work plan and evaluation plan by describing how to write project objectives, activities, and tasks. The webinar instructs attendees on key elements of an evaluation plan, emphasizes the importance of providing specific

details in the work plan and evaluation plan, and describes available tools and resources.

Screening, Identification, Referral, and Care Planning

- [Tools for Screening, Identification, Referral, and Care Planning for People with Alzheimer's Disease and Their Caregivers](#): This report describes screening instruments for detecting possible Alzheimer's disease and other dementias that can be administered by people without clinical training, and needs assessment and referral tools that are available for use. The report also includes tools used by AoA grantees for care planning, screening, and referral.

Special Topics

- [Disaster Planning Toolkit for People Living with Dementia](#): This toolkit is written to help people living with dementia, their family members, and their caregivers understand what to expect in the event of a disaster and how to prepare for it. The toolkit includes seven tip sheets and checklists for people living with dementia, their families, and others who interact with them, including friends and neighbors.
- [Faith-Related Programs in Dementia Care, Support, and Education](#): This case study report focuses on initiatives developed by five faith-based or secular organizations that include faith-related or spiritual components to support the needs of people with dementia and their caregivers. Services described in this report were developed and implemented either by a faith community or an outside secular organization.
- [Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia](#): This guide is designed to help community organizations collaborate with first responders to better serve people living with dementia. The guide explains why this issue is gaining attention, provides strategies for building successful partnerships, and describes the types of programs that can benefit people living with dementia. Also included are resources such as training materials, sample policies, tip sheets, and more.

Training Resources for Providers and Volunteers

- [Training Resources Compendium for Dementia Care Providers and Volunteers](#): This document includes training resources related to various topics on dementia such as dementia capability, people with intellectual and developmental

**Selected Resources Developed by the
National Alzheimer's and Dementia Resource Center**

disabilities and dementia, and behavioral symptom management. These resources are free of charge and come from a variety of sources including government, academia, Alzheimer's disease centers, geriatric workforce education programs, and others.