

Single Point of Entry Systems

HOME AND COMMUNITY-BASED SERVICES
FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



alzheimer's 
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A TOOLKIT FOR
THE AGING NETWORK


INTERNATIONAL

HOME AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS



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About This Toolkit: Single Point of Entry Systems

Home and Community-Based Services for People with Dementia and Their Caregivers

Individuals and families coping with dementia need simple access to accurate information and local long term care support and services. Information and assistance systems are important in increasing the use of Home and Community Based Services (HCBS) while reducing institutional care and related costs. Single points of entry (SPOE) systems offer consumers one-stop access to information, support, and linkages to local care services. SPOEs such as Aging and Disability Resource Centers (ADRCs) reduce service fragmentation and simplify access to dementia capable long-term supports and services. Area Agencies on Aging (AAAs) provide information and assistance, and many have integrated into the ADRC system. However, to best serve consumers with cognitive impairment, SPOEs such as ADRCs and AAAs must be dementia capable. **This toolkit outlines actions states and communities can take to ensure that SPOE programs are dementia capable, effectively serving individuals and family caregivers dealing with dementia.**

The Single Point of Entry Systems Toolkit:

- Explains how SPOE systems play a critical role in increasing HCBS while decreasing institutional care.
- Provides reasons to incorporate dementia capability into SPOE systems such as ADRCs and to empower consumers with dementia capable choices and access.
- Provides an array of resources that are model programs or unique examples for state officials to use when developing programs.
- Includes a step-by-step guide to enhance your SPOE as a dementia-capable system that will best serve persons with Alzheimer's disease or other dementias, their families, and caregivers. Information is provided on how to:
 1. Assist SPOE staff in identifying persons with dementia, including those with early onset dementia, and identifying any co-existing medical conditions.
 2. Support SPOE procedures that link persons and families to *basic* information about dementia.
 3. Promote SPOE processes that connect persons and families to community agencies with dementia expertise.
 4. Involve families and other caregivers to help understand care options and make decisions about supports.
 5. Engage Alzheimer's Disease Demonstration Grants to States (ADDGS) programs and SPOE staff in planning efforts.
 6. Use dementia-related multicultural and disaster preparedness information.

This toolkit provides information on promising practices, with hyperlinks to material available on the Internet.

Promising Practices: Single Point of Entry Systems

Home and Community-Based Services for People with Dementia and Their Caregivers

Why Do States/Communities Need Single Point of Entry Systems to Be Capable of Serving People with Dementia

- Alzheimer's disease and most other dementias are devastating degenerative conditions that cause memory loss, challenging behaviors, and severe functional limitations. According to the Alzheimer's Association's *2008 Alzheimer's Disease Facts and Figures* report, 70 percent of people with Alzheimer's disease and other dementias live in the community. Families provide most of their care. People with dementia also constitute a large proportion of users of home and community-based services: one-fourth of people who receive Medicare or Medicaid-funded home health care and about one-third of people who receive home and community-based services through Medicaid waiver programs have dementia.
- In the later stages of Alzheimer's disease and other dementias, people are at higher risk of nursing home placement. To ensure that people with dementia can remain in their homes and communities as long as possible, SPOE staff must identify people with cognitive impairments and refer them to appropriate community services, keeping in mind the following:
 - Most people with dementia have not been diagnosed; they and their families may be reluctant to mention the condition.
 - Many people with dementia have other serious medical conditions such as heart disease and diabetes. Individuals contacting SPOEs may identify another health problem as their main concern. Both dementia and the other condition(s) must be identified. Multiple conditions often interact in ways that negatively impact health.
 - Most people with dementia are older than 65. However, people younger than 65 can also be affected. The Alzheimer's Association estimates that about half a million Americans younger than 65 now have dementia, including some individuals in their 30s and 40s. Individuals with Down syndrome are very likely to have Alzheimer's disease before age 60.

What Are Dementia-Capable Services?

To be dementia capable, individuals who assist consumers to access HCBS must be:

- skilled at identifying people with Alzheimer's disease and other dementias,
- knowledgeable about the kinds of services that can help people with these conditions and their caregivers, and
- capable of providing linkages to community agencies that can help

SPOE staff must recognize that Alzheimer’s disease and other dementias can impair a person’s ability to understand available service options, make decisions, and plan for future long-term care. As a result, family caregivers of people with dementia often play an increasing role in care planning over time.

Single Point of Entry Systems

While SPOEs, including [ADRCs](#) and AAAs, vary greatly across the nation, states and communities can engage in key activities that can make SPOEs dementia capable:

1. Assist SPOE staff in identifying persons with dementia.
2. Support SPOE procedures that link persons and families to basic information about dementia.
3. Promote SPOE processes that connect persons and families to community agencies with dementia expertise.
4. Involve families and other caregivers to help people with dementia understand their care options and make decisions about supports.
5. Engage ADDGS programs and SPOE staff in planning efforts.

Promising Practices for Each Key Activity

1. Assist SPOE staff in identifying persons with dementia

SPOEs have taken various approaches to identify dementia-related inquiries. These approaches include:

- Adding dementia-specific questions to online self-assessment forms
- Modifying components of SPOE intake and assessment procedures
- Training SPOE telephone personnel to listen for and identify dementia
- Taking steps to reduce the stigma associated with dementia
- Modifying existing intake procedures to identify dementia as a coexisting condition
- Maintaining information about early onset dementia

Examples of approaches that states and communities can encourage SPOEs to adopt are:

A. Adding dementia-specific questions to online self-assessment forms

- **Arkansas’** ADRC uses an online [Needs Assessment](#) that includes the following item to identify dementia:

I have experienced symptoms such as:

Confusion about where I am

- Forget the names of close family members or friends*
- I have not experienced the above mentioned symptoms*

- **Minnesota's** ADRC's [Online Assessment Form](#) for individuals includes the question: "Do you have, or have you ever had severe memory problems?" This question is followed by recommendations for follow-up.

B. Modifying components of SPOE intake and assessment procedures

Minnesota modified several components of its ADRC intake and assessment:

- The computerized interview question used by state telephone information system, [Senior LinkAge Line™](#), was changed to add a question for families and other caregivers. The new question asks, "*Does the person receiving care have memory loss?*" If the caller sounds unsure, the interview form lists nine questions about possible memory loss.
- **Minnesota's** online assessment form for family caregivers and professionals includes questions about each of the Alzheimer's Association [10 Warning Signs of Alzheimer's Disease](#) and brief recommendations for follow-up.

C. Training SPOE telephone personnel to listen for and identify dementia

- **Rhode Island's** ADRC [The Point](#) trains all personnel who talk with callers seeking information to "listen for dementia." Personnel are trained to listen for words and phrases that are often signs of dementia. For example:

"She forgets to take her medicines."

"I can't leave mom alone. I'm afraid something will happen."

Additionally, The Point's staff are trained to follow-up with callers to determine whether a referral for further assessment is appropriate.

- The Alzheimer's Association trains **Minnesota's** Senior LinkAge Line™ personnel to: (1) identify dementia and (2) understand the likely effects of dementia on people's ability to access and understand information about care options, make decisions about services, and live independently in the community. The PowerPoint presentation, *Senior LinkAge Line™ Training* can be adapted for use in other states.

D. Taking steps to reduce the stigma associated with dementia

Stigma associated with dementia can make people reluctant to identify the problem; however, if the problem is not identified, then treatment is postponed and services and supports that can help remain unavailable.

- **Minnesota's** Senior LinkAge Line™ consistently uses the term "memory loss" when describing dementia.

- **Arkansas** uses words like “confusion” and “forgetfulness” in lieu of “Alzheimer’s” and “dementia.”

E. Modifying existing intake procedures to identify dementia as a coexisting condition

Identifying individuals with coexisting conditions (such as dementia and other health concerns) is important because multiple conditions often interact in ways that negatively impact health.

- **Arkansas’** ADRC online [Needs Assessment](#) (question #10) asks people to identify medical conditions by asking respondents to select from a list of fifteen conditions including Alzheimer’s or dementia, heart problems, diabetes, and other conditions.

F. Maintaining information about early-onset dementia

- Information on [early-onset dementia](#) can help SPOE staff respond to questions from people with early-onset and their caregivers. Understanding the implications of the condition can help people make informed choices about their physical and financial futures.

2. Support SPOE procedures that link persons and families to basic information about dementia

Basic information about dementia, its symptoms, treatment options, and support services are valuable for people with the condition and their caregivers. Regrettably, many people have only a vague understanding of dementia. To overcome this barrier, states and communities can support the development of SPOE procedures that either:

- Provide basic information directly to people who make dementia-related inquiries or
- Refer dementia inquiries to other community resources that can provide both basic and more extensive information about the disease and care options

A. Provide basic information directly to people who make dementia-related inquiries

SPOEs that provide basic information directly to people with dementia and their families can take advantage of the following publications from the Alzheimer’s Association, National Institute of Aging’s Alzheimer’s Disease Education and Referral Center, and the U.S. Administration on Aging:

- [10 Warning Signs of Alzheimer’s Disease](#)
- [If You Have Alzheimer’s Disease: What You Should Know and What You Should Do](#)

- [Understanding Memory Loss](#)
- [Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease](#)

B. Refer dementia inquiries to other community resources that can provide both basic and more extensive information about the disease and care options

SPOEs can refer people with dementia and their families to other sources of information that provide both basic and more extensive information, including:

- [Local chapters](#) of the Alzheimer's Association, which can provide a wide range of basic information and support. The Alzheimer's Association's Web site www.alz.org has many [fact sheets](#) and other supportive information
- The Alzheimer's Association, which has a [24/7 Helpline](#) to help callers any time of the day or night, 365 days a year

3. Promote SPOE processes that connect persons and families to community agencies with dementia expertise

Some people with dementia and their families can arrange for community services and the support they need if they are given a list of local agencies and providers. Others need more assistance to define their service needs, select a provider that can accommodate dementia-related care needs, and initiate the service. People with dementia need assistance with these tasks because of their cognitive impairments; families may need assistance because caregiver activities overwhelm them.

States and communities can suggest various resources that SPOEs can use to connect people with dementia and their families to community agencies with expertise in dementia care. These resources include local organizations that can provide direct support and national dementia resources that can provide in-depth information and support.

A. Local organizations that can provide direct support

- [Eldercare Locator](#) connects older Americans and their caregivers with sources of information on senior services. Additionally, [State Units on Aging](#), [Area Agencies on Aging](#), and county departments of human services and/or aging can provide valuable help. In rural areas, another resource that can direct people to help is the local [USDA Cooperative Extension](#) office.
- [Local chapters](#) of the Alzheimer's Association offer a wide range of dementia-specific services, including educational programs, family caregiver training, support groups for the person with dementia and the family, care consultation, and referrals to community service providers that can accommodate dementia-related care needs. Because of their expertise in dementia, many SPOEs partner with local chapters:

- Local chapter staff members in Milwaukee, **Wisconsin** have begun spending 1 day per month at the ADRC in Racine, providing training for ADRC staff and information and referrals for callers and walk-in ADRC customers.
- ADRCs in some states, such as **Arizona, Arkansas, Hawaii, Illinois, Iowa, Louisiana, Maine, and Minnesota**, have established formal partnerships with Alzheimer’s Association chapters.
- In other states, such as **Colorado, Florida** and **Georgia**, Alzheimer’s Association chapter representatives have been placed on ADRC advisory committees and boards.

B. National dementia resources that provide in-depth information and support

- The Alzheimer's Association’s [24/7 Helpline](#), supported in part by the U.S. Administration on Aging, provides reliable information and support to individuals impacted by Alzheimer’s disease or related dementias. The toll-free number, **1-800-272-3900**, is available anytime, day or night. The 24/7 Helpline serves people with memory loss and their families, caregivers, health care professionals, and the public. To assist citizens needing help after normal business hours, states can post the toll-free number on their Web sites and implement procedures to ensure that state-operated call centers refer people to the 24/7 Helpline after hours.

The 24/7 Helpline’s highly trained and knowledgeable staff can help with: (1) understanding memory loss, dementia, and Alzheimer’s; (2) dealing with challenging behaviors; (3) obtaining general information about aging and brain health; 4) developing skills to provide quality care and to find the best care from professionals; 5) making legal, financial and living arrangement decisions; and 6) handling caregiver stress. Callers who do not speak English are assisted with the use of a translation service that features over 140 languages.

- The [Carefinder™](#), supported in part by the U.S. Administration on Aging, is an online interactive resource. It provides customized recommendations on home and community care and the questions to ask based on individual needs and preferences to ensure the best care match. CareFinder™ offers ways to recognize good care, communicate effectively with care providers, plan and pay for care, and find local resources. Resources are available to assist users in finding all the information they need on one Web site.

4. Involve families and other caregivers to help people with dementia understand their care options and make decisions about supports

Some people with dementia, especially those in the early stage of their illness, will initiate contact with an SPOE. More often, family members and other caregivers will initiate the contact. Providing meaningful assistance for people with dementia

usually requires caregiver involvement. States and communities need to encourage SPOEs, like ADRCs and AAAs, to involve families and other caregivers in care planning. This is particularly important as the dementia worsens and the person loses their ability to understand care options and make decisions about services.

Involving family caregivers and providing them with needed information, support, and services can prolong their ability to provide care. SPOEs should encourage caregivers to return for additional information and assistance as the dementia progresses.

SPOEs can use available screening tools to assess family caregivers and/or refer caregivers to other community agencies for in-depth assessment. Family caregiver assessment is particularly important when the person with dementia is being discharged from a hospital, rehabilitation facility, or nursing home, and the care plan can only be implemented with services and support provided by the family.

Examples of ways in which SPOEs can involve family caregivers, assess their needs, and provide support are provided subsequently.

A. Assess the needs of family caregivers

SPOEs, such as ADRCs, are often connected to organizations involved in creating a community care plan for people with dementia. It is important that SPOEs assess needs of caregivers or refer caregivers to community organizations for a caregiver assessment.

Several states, including **Florida, Georgia, Michigan, Washington, and Wisconsin**, are field-testing a uniform caregiver screen and assessment tool developed collaboratively by the University of Wisconsin-Milwaukee and the University of Wisconsin-Cooperative Extension Service.

The Uniform Caregiver Assessment and Referral (Ucare) protocol involves teaching state and community agencies to assess caregivers actual needs to determine what services should be provided. **Michigan's** ADRCs are in the process of conducting trainings on the uniform caregiver screen. The purpose of the screen is to help determine if caregivers are experiencing high levels of stress and depression. When the ADRC staff learn to use the screen and to identify these caregivers, they can then refer the caregivers to community organizations for care consultations. At care consultations, the organization will then use a uniform caregiver assessment to obtain detailed information about the caregiver's unique situation and to identify available services that can help. Additional information about the Ucare training program and protocol is available at the Web site of the [University of Wisconsin-Milwaukee Center on Age and Community](#).

The Family Caregiver Alliance has developed a toolkit on caregiver assessment, *Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*. Section 3, "The Nuts and Bolts of Caregiver Assessment" provides

information about conducting caregiver consultations and assessments. The resource also contains [examples of state caregiver assessment tools](#).

B. Encourage families and other caregivers to return for further help when needed

Alzheimer's disease and most other diseases and conditions that cause dementia are progressive. Alzheimer's lasts an average of 4–6 years from the time of diagnosis until death, but it can last as long as 20 years from the first onset of symptoms. As dementia progresses, the needs of the person with the disease and their caregiver will change. States and communities should encourage SPOE staff to invite families and other caregivers to return to the SPOE and other community organizations for assistance and referrals in addressing future care needs.

5. Engage ADDGS programs and SPOE staff in planning efforts

Over the past 15 years, all 50 states plus the District of Columbia and Puerto Rico have received one or more [Alzheimer Disease Demonstration Grants to States](#) (ADDGS) grants from the U.S. Administration on Aging. Using grant funds, states have created innovative services for people with dementia and their families, increased dementia care expertise, and established community referral networks.

State ADDGS program staff have been partnering with ADRC staff in their planning efforts. State government dementia care experts and their partner organizations can provide information about dementia resources and can facilitate connections to community service providers. Some states have used ADDGS grant funds to enable their ADRCs to become more dementia capable. Examples of states that have used their ADDGS funding to collaborate with their ADRCs follow:

- **Maine** is using ADDGS grant funds to support an Alzheimer's expert at the Eastern Agency on Aging, one of the state's AAAs and its first ADRC. The ADDGS grant also supports a family caregiver support program that is based at the Eastern Agency on Aging. People who contact the ADRC about persons with dementia are referred immediately to the on-site Alzheimer's expert and family caregiver support program.
- **Minnesota** used ADDGS funds to make its ADRC dementia capable in ways described in the first section of this toolkit. For example, it revised the referral database used by staff of the state's telephone information system, [Senior LinkAge Line™](#), so that when contacts about a person with dementia are identified, the caller is referred first to the Alzheimer's Association for help with defining care needs and selecting service providers. Changes were also made to computerized intake and self-assessment forms.
- **Rhode Island** used ADDGS funds to support two half-time staff members at the ADRC. The two staff members are dementia specialists; they provide counseling, referrals, and assistance in arranging services and supports for

people with dementia, with backup from the local Alzheimer's Association chapter as needed.

- **North Carolina** has supported an innovative ADDGS program, [Project C.A.R.E.](#), (Caregiver Alternatives to Running on Empty) which provides comprehensive respite support and linkage to services for family caregivers by a family consultant. The family consultant is based in the Alzheimer's Association chapter and works closely with the state's ADRCs in two counties to encourage them to refer families of people with dementia to Project C.A.R.E.
- **West Virginia** supports an innovative program, Continuum of Contact, which provides a structured 6-month family caregiver information and support program that is based at the Alzheimer's Association chapter. The state's ADRCs have been encouraged to refer families of people with dementia to the program. ADDGS grant funds are also being used to support ADRC involvement in a project to increase the availability and use of dementia-capable hospice care.

Additional Information

The U.S. Administration on Aging has developed eight toolkits in this series that focus on different aspects of providing home and community based services to people with dementia and their caregivers. These online toolkits are available at the [Administration on Aging Alzheimer's Disease Program webpage](#). Toolkit titles include:

1. Consumer-Directed Care
2. Disaster Preparedness
3. Resources for Individuals and Families
4. Serving African American Families
5. Serving Asian and Pacific Islander Families
6. Serving Hispanic Families
7. Single Point of Entry Systems
8. Supporting Family Caregivers