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Alzheimer's Disease Demonstration Grants to States Program: Minnesota

Final Report

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EXECUTIVE SUMMARY

The Minnesota Alzheimer's Disease Demonstration Grants to States (ADDGS) grant projects have operated since 2000 to expand access to dementia care and to demonstrate a comprehensive approach to meeting the needs of people with Alzheimer's disease and other dementias. The current ADDGS grant employs the Chronic Care Networks for Alzheimer's Disease model, which calls for an integrated approach consisting of four components:

- dementia identification, including linkage to both medical and social care resources;
- memory loss assessment and diagnosis, recognizing the critical role played by the physician and the medical care team in patient care;
- joint care management, in which the patient's care is coordinated by a team of medical and social providers; and
- training and support services, combining and coordinating the education of providers, families, and clients with social care support for the entire family.

The Minnesota ADDGS grants have been part of a comprehensive approach to support people with Alzheimer's disease and other dementias and their families. The Minnesota grants are relatively unique among ADDGS grants in their focus on the health and long-term care systems, rather than on the long-term care system alone. The Chronic Care Networks for Alzheimer's Disease model provides a strong conceptual framework to organize the activities of the second grant, giving it a unifying theme.

Under direction of the Minnesota Board on Aging, the grants have conducted their activities in partnership with the state Community Services/Service Development grant program and the Alzheimer's Association Minnesota and North Dakota Chapter. Local grant efforts have operated under the direction of Faith-in-Action, Area Agencies on Aging, and Living at Home/ Block Nurse programs and local health care systems.

The first Minnesota ADDGS grant (2000–2004) conducted a series of statewide activities which increased the statewide availability of information and dementia education for professional staff and the public. The grant worked with the state Senior LinkAge Line™—the state central information source for older citizens—to increase the resources available to persons with Alzheimer's disease and their caregivers. The grant also supported the development of a number of local projects that provided culturally appropriate services to ethnic communities and to persons in rural areas.

Employing the Chronic Care Networks for Alzheimer's Disease model, the current ADDGS grant (2004–2007) is working to develop five main initiatives (***Exhibit ES-1***).

Exhibit ES-1.
Main Components of the 2004–2007 Working Together Grant

- Development of a statewide "no wrong door" early identification system to serve individuals with dementia and their caregivers.
- Development of tools for a statewide system of community-based dementia identification.
- Establishment of dementia assessment, treatment, referral, and care coordination services in Minnesota health care systems.
- Provision of a community-based system of care coordination and respite service delivery.
- Comprehensive in-depth education in dementia identification and care for both the community services system and the medical system.

At the state level, the grant is working with the state Senior LinkAge Line™ to identify and help seniors with memory loss and caregivers in need of support. With grant support, the state Aging and Disability Resource Center now provides services for families dealing with Alzheimer's disease. The grant has increased awareness of Alzheimer's disease through a statewide education program of videoconferences and other training programs. Additionally, the grantee is working with other agencies in the state to train dementia-capable caregiver coaches.

The five local pilot projects have conducted activities addressing all parts of the Chronic Care Networks for Alzheimer's Disease model. Pilot projects are identifying persons with memory loss and their caregivers through community outreach activities and clinic-based identification systems. At most of the sites, pilot projects have established direct access to assessment and diagnosis services in a hospital or medical clinic setting. Care management activities at the pilot sites have demonstrated the feasibility of direct cooperation with medical clinics and generated protocols for patient management within the medical system. The pilot projects have also demonstrated approaches for providing direct support and advice to families. Local educational materials and strategies developed by the pilot projects have informed providers and families of available support services. The pilot efforts provide these services in a culturally appropriate manner in rural areas and to ethnic minority communities in urban settings.

Through these efforts, the current Minnesota ADDGS grant project is providing support programs for people with Alzheimer's disease and their caregivers that address the four principles of the Chronic Care Networks for Alzheimer's Disease model. The principal findings of this study are presented in ***Exhibit ES-2***.

Exhibit ES-2.
Principal Findings from the Minnesota Case Study

The Minnesota ADDGS grant project is providing support for caregivers and people with Alzheimer's disease through application of the four principles of the Chronic Care Networks for Alzheimer's Disease model. The project has:

- Increased awareness of Alzheimer's disease both on a statewide level by outreach through the state's Senior LinkAge information line and in selected rural and urban communities through direct community outreach.
- Developed assessment and diagnosis services in hospital and medical clinic settings and protocols for referral by medical providers to community social supportive services.
- Established systems of joint care management through direct cooperation between community social support providers and medical clinics.
- Implemented a model for supporting care management plans in situations where community social support providers do not have as direct a relationship with medical providers.
- Instituted an array of educational programs at the statewide level. The project has made educational materials and training available to providers and families to assist them in identifying available support services. The project also developed web-based sources of long-term care information.
- Supported respite and other support services for families, and worked with other state officials to develop a program which will train and certify caregiver coaches for families across the state.
- Worked to integrate its programs and activities into existing state and local systems to promote sustained systems change.

Under the leadership of the Minnesota Board on Aging, grant programs are being institutionalized in the activities of the state Department of Human Services, Aging and Disability Resource Center, and the Senior LinkAge Line™. Educational programs are being developed in cooperation with the Alzheimer's Association Minnesota and North Dakota Chapter. The local projects sponsored by the grant have integrated their activities into the work of hospitals, clinics, and ongoing community service organizations.

SECTION 1
INTRODUCTION: OVERVIEW OF ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. A person with late-stage Alzheimer's disease requires constant supervision, support, and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of their care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard-to-reach and underserved people with Alzheimer's disease or related disorders" (U.S. Administration on Aging, 2006).

The ADDGS program is addressing how to deliver effective services to persons with Alzheimer's and other dementias and their caregivers, especially to underserved and hard-to-reach populations. The purpose of the ADDGS program is to enhance the ability of states to provide the services and supports needed to sustain the community-based Alzheimer's disease care system. The program does this in two ways: by demonstrating innovative service models of Alzheimer's services that can be replicated and sustained in the community and by stimulating systemic change to increase the responsiveness of states' long-term care systems to the needs and preferences of persons with dementia and their families.

This report is one of four case studies conducted by the ADDGS National Resource Center in 2006 on the activities of selected state programs.[1] The goals of the case studies are:

- to document "promising practices,"
- to identify policy issues relevant to providing services to people with Alzheimer's disease and their families,
- to identify implementation barriers and ways of overcoming them, and
- to assess how selected states are addressing the goals of the ADDGS program.

The Minnesota ADDGS program was chosen because of its implementation of the Chronic Care Networks for Alzheimer's Disease model of integrated care for persons with dementia (Chronic Care Networks for Alzheimer's Disease, http://www.nccconline.org/about/alzheimers.htm). The Chronic Care Networks for Alzheimer's Disease model was developed jointly by the National Chronic Care Consortium (NCCC) and the

[1] The other case studies looked at New York, which focused on integrating care for developmentally disabled people with Alzheimer's disease; Michigan, which focused on a mental health perspective on Alzheimer's disease; and a cross-state examination of programs focusing on minority populations.

Alzheimer's Association. Integrated care under the Chronic Care Networks for Alzheimer's Disease model takes a comprehensive approach, including the coordination of acute, primary, and long-term care for the individual with Alzheimer's disease as well as support for the caregiver. In order to address this wide range of care services, NCCC and the Alzheimer's Association Chronic Care Networks for Alzheimer's Disease demonstration project brought managed care organizations and Alzheimer's Association chapters together into partnerships. Acting together, managed care organizations and Alzheimer's Association chapters provided diagnoses and care management for the patient and information and support for the caregiver. Through the managed care organizations, the project used a risk-based management approach, with financial incentives to provide the most efficient and appropriate care to address the needs of each patient and to support the patient and caregiver as a family unit (Chronic Care Networks for Alzheimer's Disease, undated). ***Exhibit 1*** lists the Chronic Care Networks for Alzheimer's Disease principles which are being implemented by the current Minnesota ADDGS grant.

Exhibit 1.
Chronic Care Networks for Alzheimer's Disease Principles Used by the Minnesota Working Together ADDGS Grant, 2004–2007

- Dementia identification, including linkage to both medical and social care resources.
- Memory loss assessment and diagnosis, recognizing the critical role played by the physician and the medical care team in patient care.
- Joint care management, in which the patient's care is coordinated by a team of medical and social providers.
- Training and support services, coordinating the education of providers, families, and clients with social care support for the entire family.

Source: Chronic Care Networks for Alzheimer's Disease.

Minnesota has implemented two ADDGS grant projects. The first grant was awarded in 2000 and operated until 2004. The second ADDGS grant, the Working Together project, was awarded in 2004 and runs until June 2007. This paper examines how the Minnesota ADDGS program has used the Chronic Care Networks for Alzheimer's Disease model to support persons with Alzheimer's disease and their families. The research questions for this study ask how the Minnesota ADDGS grants have employed the Chronic Care Networks for Alzheimer's Disease model to:

- increase Alzheimer's disease awareness and the identification of persons with Alzheimer's disease,
- enhance the availability and quality of assessment services for persons with Alzheimer's disease and their families within the overall health system,

- support persons with Alzheimer's disease and their families through effective care management, and

- expand the availability of education and training about Alzheimer's disease and provide high-quality support services for persons with Alzheimer's disease and their families.

By focusing on the relationship between the health and long-term care systems rather than on the long-term care system alone, the grantee is taking a different approach from many of the other ADDGS projects. The grantee is working directly with medical providers in developing a comprehensive approach to coordinated medical care and supportive services for people with Alzheimer's disease and other dementias. At the state level, the grant is implementing activities to identify persons with dementia, to support families and professional caregivers, and to educate them about Alzheimer's disease and community supports. At the local level, five local grant initiatives are providing community-based services and developing models of cooperation with medical clinics and hospitals. The five main components of the Working Together grant are presented in ***Exhibit 2.***

Exhibit 2.
Main Components of the 2004–2007 Working Together Grant

- Development of a statewide "no wrong door" early identification system to serve individuals with dementia and their caregivers.

- Development of tools for a statewide system of community-based dementia identification.

- Establishment of dementia assessment, treatment, referral, and care coordination services in Minnesota health care systems.

- Provision of a community-based system of care coordination and respite service delivery.

- Comprehensive in-depth education in dementia identification and care for both the community services system and the medical system.

The grantee applied Chronic Care Networks for Alzheimer's Disease principles to implement these grant components on a statewide level and through the five locally based pilot projects, four located in rural settings and one operating in urban neighborhoods of eastern St. Paul.

The principal findings of the Minnesota case study are presented in ***Exhibit 3***.

Exhibit 3.
Principal Findings from the Minnesota Case Study

The Minnesota ADDGS grant project is providing support for caregivers and people with Alzheimer's disease through application of the four principles of the Chronic Care Networks for Alzheimer's Disease model. The project has:

- Increased awareness of Alzheimer's disease on a statewide level by outreach through the state's Senior LinkAge information line and in selected rural and urban communities through direct community outreach.
- Developed assessment and diagnosis services in hospital and medical clinic settings and protocols for referral by medical providers to community social supportive services.
- Established systems of joint care management through direct cooperation between community social support providers and medical clinics.
- Implemented a model for supporting care management plans in situations where community social support providers do not have as direct a relationship with medical providers.
- Instituted an array of educational programs at the statewide level. The project has made educational materials and training available to providers and families to assist them in identifying available support services. The project also developed web-based sources of long-term care information.
- Supported respite and other support services for families, and worked with the state to develop a program which will train and certify caregiver coaches for families across the state.
- Worked to integrate its programs and activities into existing state and local systems to promote sustained systems change.

Information for this case study was gathered by reviewing Web sites and administrative files at the U.S. Administration on Aging and by conducting an in-person site visit in July 2006 in St. Paul, Minnesota. As part of the site visit, RTI staff interviewed ADDGS staff, state officials, research experts, providers, consumer groups, and others.

SECTION 2
OVERVIEW OF THE MINNESOTA ADDGS PROJECTS

The Minnesota ADDGS Grantee

The recipient of the ADDGS grant is the Minnesota Board on Aging, a free-standing agency that reports directly to the governor. The Minnesota Board on Aging operates in close cooperation with, but is not responsible to, the Aging and Adult Services Division of the state Department of Human Services. The Director of the Minnesota Board on Aging is also the Director of the Division of Aging and Adult Services. Both of the state ADDGS grants have been implemented by the Minnesota Board on Aging through contracted staff reporting to the Director of the Minnesota Board on Aging and the Division of Aging and Adult Services.

As the State Unit on Aging, the Minnesota Board on Aging promotes policies to the state legislature, the Governor, and state agencies that reflect the needs of older Minnesotans. Its strategic plan calls for promoting senior-friendly communities, increasing consumer direction in services for seniors, improving integration and chronic disease management in the health care system, and using technological advances in communication and information management to improve access and quality in service delivery. Since 2000, the Board on Aging has been developing a strategy to provide a statewide system of integrated care for the state's older population.

The Minnesota Alzheimer's Demonstration Project: 2000–2004

The Minnesota Alzheimer's Demonstration Project was the first Minnesota ADDGS grant. Although it began its operations prior to the publication of the Chronic Care Networks for Alzheimer's Disease final report, grant activities were largely consistent with the model's approach. The first ADDGS grant increased the statewide availability of information and dementia education for professional staff and the public. It also enhanced the ability of the state to identify people with Alzheimer's disease and to communicate with individuals and families in need of services. The grant addressed the Chronic Care Networks for Alzheimer's Disease's emphasis on comprehensive screening and assessment by developing a memory assessment clinic in Duluth. This first grant also modeled culturally appropriate and rural community-based service models of assistance for clients and caregivers, and increased the availability of respite and adult day care. To make these services more responsive to members of minority groups, the grant developed culturally appropriate educational materials for the Hispanic, Hmong, Korean, and African American communities.

A major activity of the first ADDGS grant was the Hospital-Based Dementia Identification Project, developed with funding from the state Community Service/Service Development Program. Operating within a hospital setting, this initiative developed systems for early identification of individuals with Alzheimer's disease, improved care coordination, and caregiver support. It also established ongoing linkages among health care providers, long-term care services, and the Alzheimer's Association Minnesota-North Dakota Chapter (Alzheimer's Association Chapter). The initiative, which has now expanded to two additional hospitals, uses the Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia developed by the Chronic Care Networks for Alzheimer's Disease project (Chronic Care Networks for Alzheimer's Disease, 2003b). The initiative's operations are based

at St. Joseph's Hospital in St. Paul, with affiliates including other major hospitals, county governments, the Minnesota Board on Aging, and the Alzheimer's Association Chapter. Of the 6,632 patients at St. Joseph's hospital who were screened for memory loss, 20 percent showed signs of dementia, demonstrating the importance of developing dementia capability in the hospital setting. The initiative developed tools and strategies for staff training, dementia identification protocols and referral pathways for medical care, an assessment protocol, and care consultant services for families. These tools and strategies are available to the second ADDGS project and the staff of the initiative serves as mentors and trainers for the ADDGS pilot projects in the second grant.

A statewide activity of the first ADDGS grant was the educational program "Black Clouds, Sunny Days." Begun in 2002, this depression education campaign was designed to increase awareness of depression and its symptoms, challenge the notion that depression is an unavoidable result of aging, and encourage people to seek care for depression. The grant produced 70,000 consumer brochures, which continue to be distributed under the current ADDGS grant project, to help identify individuals with dementia and to encourage them to seek assessment and support. The original education campaign also produced resource kits for health care personnel and Older Americans Act nutrition site managers, a guide for educators, and educational materials for physicians, including a CD-ROM on depression, medication, and screening tools. Training presentations were produced for consumers, county public health staff, and Area Agency on Aging program staff. Videoconference training was conducted, and taped copies were later distributed to service providers and state and county agencies by the grant project. A consumer evaluation for the "Black Clouds, Sunny Days" campaign found that 95 percent of people who participated in workshops learned to identify the symptoms of depression, learned about the services available for people with depression, and were more confident seeking resources or talking to a doctor. Additionally, 86 percent learned techniques for managing depression.

Another state-level initiative of the first ADDGS grant was its work with the state Aging and Disability Resource Center, which provides information and assistance services to the state's seniors. The first ADDGS grant worked with the Aging and Disability Resource Center to update its resource database to include additional information on Alzheimer's disease and dementia-related programs.

The first grant also developed five pilot projects. Two pilot programs of culturally appropriate services operated in St. Paul, providing culturally appropriate services to the Hispanic and Hmong communities. One pilot project provided outreach, education, and adult day care services to the Hispanic community in partnership with the nonprofit Chicanos Latinos Unidos En Servico. Culturally appropriate adult day services were provided to the Hmong community by another pilot project through a partnership with Wingspan Life Resources, a St. Paul-based nonprofit service provider.

The other three pilot projects were rural community models. These projects provided services such as dementia-competent adult day care services, dementia training for volunteers, in-home volunteer companion and respite services, paid in-home respite services, and screenings by an in-home nurse dementia/memory loss specialist. While providing respite services to the Chippewa community in the northern part of the state, one pilot project found that congregate

adult day care was not effective in the Chippewa community because of the community cultural value that the family should provide care for its elders. Pilot project staff responded by introducing in-home respite, which was more culturally appropriate. Another pilot project developed a memory assessment clinic in partnership with St. Mary's Hospital in Duluth. "Joy Kits," collections of simple activity materials for use by individuals with Alzheimer's disease, were developed by one of these pilot projects. These kits were disseminated throughout Minnesota and nationally with U.S. Administration on Aging support and are in use by the pilot projects operating under the second grant. A manual for creating Joy Kits is available on the Board on Aging Web site at http://www.mnagingproviders.org/memorycare/pages/Joy%20Kit%20Manual.pdf.

The Minnesota Working Together Project: 2004–2007

The Working Together ADDGS project bases its overall approach on the Chronic Care Networks for Alzheimer's Disease model, which provided the project with a comprehensive approach to coordinated medical care and supportive services for people with Alzheimer's disease and other dementias.

- At the state level, the Working Together ADDGS grant has applied the Chronic Care Networks for Alzheimer's Disease model to dementia identification assistance and outreach activities. The dementia identification information and assistance activities are designed to connect people with dementia and their families to supports as quickly as possible no matter where they enter the service system. The dementia identification outreach work aims to raise public awareness about dementia and to encourage families to seek diagnosis and support services. Training has been offered statewide and includes videoconferences for professional family support staff, on-site training for volunteers and family caregivers, support services for caregivers, and dementia capacity training for caregiver coaches. Dementia-competent online caregiver assessment and support tools are also being provided through the Aging and Disability Resource Center.

- At the local level, the Working Together ADDGS grant is applying all the strategies of the Chronic Care Networks for Alzheimer's Disease model through activities at five pilot projects in rural and urban localities around the state.

SECTION 3
ORGANIZATION OF THE WORKING TOGETHER ADDGS GRANT

The Working Together project is a combination of statewide initiatives and local pilot projects. A major feature of the grant is the role of the project manager in communicating the principles of the Chronic Care Networks for Alzheimer's Disease to the pilot projects, so that they are focused on the same goals.

Working Together Statewide Initiatives

At the statewide level, the Minnesota ADDGS grant has initiatives in dementia identification and education. The grant is working to:

- integrate dementia identification into the services of the state Senior LinkAge Line™, the state's free telephone and assistance service for seniors;
- make dementia competent information and supports available through Aging and Disability Resource Center educational and assistance efforts;
- educate healthcare professionals and caregivers statewide about dementia identification practices, and dementia care tools and supports, in cooperation with the Alzheimer's Association Minnesota-North Dakota Chapter;
- build a statewide network of dementia-competent caregiver "coaches" through the state Department of Human Services; and
- develop access to web-based long-term care information and support in cooperation with the Minnesota Board on Aging.

Working Together Pilot Projects

At the local level, the current Minnesota ADDGS grant has funded five pilot projects. The roles and responsibilities of the pilot projects are outlined in ***Appendix 1***. The pilot projects are described in ***Exhibit 4***.

Exhibit 4.
Pilot Projects of the Minnesota Working Together ADDGS Grant, 2004–2007

Pilot Name	Service Area	Activities
Arrowhead Dementia Identification and Care Companion Pilot	Duluth and seven surrounding rural counties in northeastern Minnesota	Under the direction of the Arrowhead Area Agency on Aging and largely implemented by the Northern Minnesota Regional Office of the Alzheimer's Association Chapter, the pilot provides dementia capacity-building education and care consultation support to providers and dementia education, training, and support to families.

(continued)

Exhibit 4.
Pilot Projects of the Minnesota Working Together ADDGS Grant, 2004–2007 (continued)

Pilot Name	Service Area	Activities
Bridge Partnership Memory Loss Pilot	Eastern St. Paul, Payne-Phalen neighborhood	Under the direction of the urban-based Bridge Partnership and targeting the Hispanic and Hmong communities, the partnership is led by the Payne-Phalen Living at Home/Block Nurse Program. Using a culturally diverse team model, the pilot project identifies persons with memory loss in these communities and provides them and their families with care planning and coaching, education, community services, and assistance in gaining medical care.
Kandi-Meeker Cash and Counseling Memory Loss Pilot	Grove City and Atwater and surrounding rural areas of southwestern Minnesota	A cooperative effort between two small Living at Home/Block Nurse Programs, these agencies serve the small towns and the surrounding rural area with one staff person each, either a nurse or a social worker. Both agencies in this pilot project are implementing a grant-funded Cash and Counseling program. They also provide meals, deliveries, companionship, transportation, light housekeeping and chores, and nursing.
Memory Disorders Clinic Partnership Pilot	St. Cloud and four surrounding counties in central Minnesota	Directed by an independent board and supported by a number of organizations, including the Central Minnesota Council on Aging and the Alzheimer's Association Chapter, the pilot project operates the interdisciplinary Central Minnesota Memory Disorders Clinic. Although the clinic is independent, its office is within an outpatient clinic facility operated by Health Partners, one of the largest health care systems in the state. The clinic is staffed by a geriatric nurse practitioner, social worker, occupational therapist, and a volunteer physician medical director. The clinic accepts referrals from physicians and individuals and provides in-depth interdisciplinary assessments and community care plans for individuals with memory disorders. It also works in partnership with regional Faith-in-Action[2] projects and long-term care consultants in four counties to provide caregiver support.

(continued)

[2] Faith-in-Action, a Robert Wood Johnson Foundation-sponsored program started in 1994, organizes volunteers on a local basis from churches, synagogues, mosques, and other houses of worship, as well as the community at large to help people in need by providing nonmedical assistance such as running errands, providing a ride, or friendly visiting.

Exhibit 4.
Pilot Projects of the Minnesota Working Together ADDGS Grant, 2004–2007 (continued)

Pilot Name	Service Area	Activities
Waseca Medical Center—Mayo Health System Volunteers-in-Action Memory Loss Partnership Pilot	The City of Waseca and Waseca County in Southern Minnesota	Implemented by a caregiver support program in operation at Waseca Medical Center, the pilot is located at Waseca Medical Center. Mayo Health System provides funding for a half-time volunteer coordinator and in-kind office support. The caregiver support program received a Faith-in-Action grant in 1995 and has had state Community Services/Service Development grant funding since 2001. The pilot provides clinic-based dementia identification, assessment, care planning and coordination, and support services, particularly respite.

Key Project Partners

The projects main partners are the following:

- *Alzheimer's Association Minnesota-North Dakota Chapter*, which uses its expertise in Alzheimer's disease and other dementias as the primary educator and substance expert for all aspects of the grant. Materials produced by the Alzheimer's Association Chapter for the grant include statewide videoconference trainings and a folder of Memory Loss fact sheets about Alzheimer's disease, which has been widely used by the pilot projects. The Alzheimer's Association Chapter was also a participant in the Minneapolis-St. Paul project site of the Chronic Care Networks for Alzheimer's Disease demonstration. With this experience and its dementia expertise, the Alzheimer's Association Chapter has been instrumental in implementing the Working Together project.

- *Minnesota Community Services Service Development program*, a state-funded program to support demonstration programs that change the balance of the long-term care system toward home and community-based services. By integrating multiple services, replicating successful models, and using nonpublic funding and volunteer support, the program hopes to serve more people in the community and to reduce the costs associated with fragmented or duplicated services. All of the organizations operating the ADDGS grant pilot projects are co-funded by the Community Services/Service Development program. The program is funded at about $6 million a year, of which 10 percent or approximately $600,000 per year supports ADDGS program efforts.

- *Aging and Disability Resource Center/Senior Linkage Line*™, which is part of a comprehensive approach to long-term care planning and decision-making. The Senior LinkAge Line™ is a free telephone information and assistance service for seniors and provides health care counseling to older citizens. The ADDGS grant project is

working to integrate dementia identification and support activities into Senior LinkAge Line™ operations and the rest of the Aging and Disability Resource Center program. The Aging and Disability Resource Center receives grant support from the U.S. Administration on Aging, the Centers for Medicare & Medicaid Services, and the Minnesota Department of Human Services Community Service/Service Development grant program.

- *Elderberry Institute,* a nonprofit organization, which is the resource center for the Living at Home/Block Nurse Program. The first Living at Home/Block Nurse Program was organized in 1981 in St. Paul with the establishment of a neighborhood Block Nurse program to provide local one-on-one health support services for community elders. St. Paul was selected in the 1980s as a demonstration site for the national Living at Home Program, a Commonwealth Fund and Pew Memorial Trusts-funded program providing neighbor-to-neighbor community support for elders. The two programs combined in 1987. For the first ADDGS grant, the Elderberry Institute provided management support services to 20 Living at Home/Block Nurse Programs who provided 112,653 hours of volunteer respite and other services to 477 people with dementia and their caregivers. Under the Working Together grant, the Elderberry Institute provides grant management and fiscal agent services to the two Living at Home/Block Nurse Programs which are implementing a cash and counseling pilot project.

SECTION 4
IMPLEMENTATION OF THE WORKING TOGETHER PROJECT

The Working Together project has initiatives on both the statewide and local levels. Grant activities are described here as they relate to each of the four principles of the Chronic Care Networks for Alzheimer's Disease model.

Dementia Identification Activities

Identification of individuals with Alzheimer's disease and other dementias as early as possible in the development of the disease is a key element in ensuring the highest possible quality of life for both patients and caregivers. The Chronic Care Networks for Alzheimer's Disease model made identification a priority after determining that dementia frequently was not being identified or was being identified very late in healthcare settings. Alzheimer's Association Chapter staff report that caregivers typically do not approach them for help until after the person's condition has progressed to a crisis point. As a result, both people with Alzheimer's disease and informal caregivers fail to receive needed support during the early stages of the illness. By bringing higher visibility to Alzheimer's disease, the Working Together grant is seeking to identify patients with memory loss and provide support to caregivers earlier in the progression of the disease so that they can be linked with services and perhaps treatments.

Statewide Initiatives

Building on efforts by the first Alzheimer's Disease Demonstration Grants to States (ADDGS) grant, the Working Together project is working with the state Aging and Disability Resource Center to embed dementia identification strategies within the Senior LinkAge Line™, the state's telephone information and assistance service for seniors. Under the first grant the Senior LinkAge Line™, which provided almost 100,000 unduplicated contacts in 2005, updated its database to include additional information on Alzheimer's and dementia-related programs.

The Working Together grant has worked with the Aging and Disability Resource Center to introduce changes to the Senior LinkAge Line™ web-based interview protocol. These changes are based on the early identification tools developed by the Chronic Care Networks for Alzheimer's Disease, such as the Alzheimer's Association Ten Warning Signs (Chronic Care Networks for Alzheimer's Disease, 2003b). Drawing on those tools, the Senior LinkAge Line™ has added questions to the computer-guided interview to enhance its dementia screening and referral capability. The Senior Linkage Line™ referral protocol and client referral procedures are presented ***Appendix 2***. The Working Together project is also working with the Senior LinkAge Line™ to upgrade its client tracking system to monitor clients with memory loss.

With grant assistance, the Senior LinkAge Line™ has developed a four-part strategy to more effectively identify and assist persons with memory loss and their caregivers. First, the Alzheimer's Association Chapter is providing training for Senior LinkAge Line™ specialists in the use of dementia identification tools and strategies for communicating with people with memory problems. With this training, Senior LinkAge Line™ specialists will be better able to recognize the signs of memory problems in the individuals they interview, and to provide them and their caregivers with appropriate referral resources.

Second, all caregiver callers are now asked, “Does the person receiving care have memory loss?” Callers responding “yes” are asked additional questions to facilitate connection to services to support both the patient and caregiver.

Third, in consultation with the ADDGS grant, the Senior LinkAge Line™ has also revised the protocols used by Senior LinkAge Line™ specialists in providing information and support through the MinnesotaHelp.info database. The MinnesotaHelp.info database is a public online reference source for community services that also serves as the information source for the Senior LinkAge Line™ specialists. The database gives Senior LinkAge Line™ specialists ready access to referral information for clients. The protocol revisions introduce entries for memory loss and dementia services into the system of coding used by the specialists in accessing the database. By using these codes, Senior LinkAge Line™ specialists consulting the database will refer individuals with memory issues to the Alzheimer’s Association Chapter. Previously, these individuals were referred to nursing homes or assisted living facilities. The Working Together grant, in cooperation with the Aging and Disability Resource Center, has also developed an online Consumer Decision Tool for Seniors, which helps consumers to search the www.MinnesotaHelp.info database. Community resources in the database can be searched by location, key word, agency, or type of service needed.

The fourth strategy is for Senior LinkAge Line™ specialists to connect callers with memory loss directly to Alzheimer’s Association Chapter support personnel. Under this system of “live” call transfers, the Senior LinkAge Line™ specialist transfers a client call directly to a “memory care expert.” Previously, Senior LinkAge Line™ specialists only gave the caller the telephone number of the Alzheimer’s Association Chapter. Chapter staff believe that people often did not make that call for help because they were intimidated by the idea of contacting someone about Alzheimer’s disease. Alzheimer’s Association staff also hope that the term “memory care expert” will be less frightening to families. The Alzheimer’s Association Chapter is upgrading its helpline with a core group of volunteers and expects an increasing number of new client contacts.

The Working Together grant is also collaborating with the Aging and Disability Resource Center to make information about memory loss a part of other Aging and Disability Resource Center outreach efforts. The Aging and Disability Resource Center and the Working Together grant have printed 64,000 informational cards with the 10 warning signs of Alzheimer’s disease and information about Senior LinkAge Line™ and the Alzheimer’s Association Chapter. The informational card is reproduced in ***Appendix 3.*** These cards, part of the Aging and Disability Resource Center’s “Age Well, Live Well, Plan Well, Care Well” marketing campaign, are available in kiosks with other Aging and Disability Resource Center information. The kiosks are located in medical clinics, libraries, banks, and other community facilities throughout the state. Memory care screening and referral will also be offered at Aging and Disability Resource Center offices around the state. Beginning in November 2006, clients were able to meet with Aging and Disability Resource Center counselors, who are trained to provide assistance to individuals and families for memory loss as well as for other long-term care needs.

Additionally, the Working Together project is continuing to distribute materials from the “Black Clouds, Sunny Days” campaign of the earlier ADDGS Alzheimer’s Demonstration Project to raise public awareness of depression as a symptom of dementia.

Pilot Site Activities

The pilot sites are engaged in a range of activities to identify persons with memory loss and their caregivers through outreach to the community. They are also developing relationships with medical clinics and physicians and working to establish protocols for medical and long-term care providers to identify individuals with memory loss. Three of the pilot projects are working to establish relationships with clinics and hospitals that will allow them to identify and refer individuals with dementia to appropriate medical care. The other two pilot projects operate within clinics and provide interdisciplinary evaluation for dementia patients. They also provide professional consultation and training for staff of the outpatient clinics and hospitals with whom they work.

Pilot community outreach activities include training programs for professionals and direct training contacts with individuals and families. Pilot projects are training care professionals through classes and by consulting with community physicians about particular cases. The Living at Home/Block Nurse Programs and other pilot projects are integrating their outreach to individuals with Alzheimer's disease into their overall community outreach programs. These organizations develop personal connections with individuals and families in minority communities to gain their trust. The trusting relationship they establish with communities enables them to identify memory problems as a part of their overall effort to support their clients.

Arrowhead Dementia Identification and Care Companion Pilot. The Arrowhead Dementia Identification and Care Companion pilot serves a predominantly rural seven-county area and the city of Duluth. The pilot project has developed a dementia-identification initiative to train staff from community services, county long-term care staff, parish nurses, faith-based support services, and health care organizations about the warning signs of dementia. This program has provided training sessions in 16 communities of the pilot project service area. The sessions, with instructors trained in dementia care, included instruction in risk factors, tools for detecting memory loss, and protocols for referring persons with memory loss and their families for services. A half-time care consultant has been hired to provide consultation services to families and develop referral relationships with medical clinics and providers. Pilot project staff have also provided area medical clinics with Alzheimer's Association Chapter Memory Loss folders. Additionally, a pilot-sponsored and Community Services/Service Development funded caregiver coach, located at the St. Mary's/Duluth Clinic Health System in Ely, is working with the Alzheimer's Association and the clinic manager to more fully engage clinic staff in dementia identification efforts. Through a newly funded Community Services/Service Development grant to the Arrowhead Area Agency on Aging, the pilot project plans to support the development of further dementia identification capabilities in four target areas in northeast Minnesota, including Duluth. Community work groups/consortiums have been developed in the target areas, and the St. Luke's Health System is expected to be a major partner.

Bridge Partnership Memory Loss Pilot. The Bridge Partnership pilot, under the leadership of the Payne-Phalen Living at Home/Block Nurse Program in urban St. Paul, has integrated dementia identification into its core mission of providing services to elders in the community. The pilot has trained its staff to recognize signs of memory loss, and has added the 10 warning signs of Alzheimer's disease to its client screening process. Much of the pilot program's outreach activities are conducted within the Hispanic community. With support from

a $10,000 grant from MetLife, Payne-Phalen and the Alzheimer's Association Chapter are developing outreach materials in Spanish.

Pilot program staff report that the most important element in dementia identification in the Hispanic community is establishing trust between program staff and the community through cultural awareness and respect. Staff members report that it is important to be sensitive to issues of immigration status and to community taboos against acknowledging dementia. Pilot project staff have found that they must address a broad range of family needs to assist family members with memory loss.

Kandi-Meeker Cash and Counseling Memory Loss Pilot. The Grove City and Atwater Living at Home/Block Nurse Programs are engaged in identification efforts in their rural counties. These two programs have integrated dementia identification into their core mission of providing services to elders in the community. In Grove City, the coordinator knows many of the people in the community and has made informal contacts with families and physicians. The coordinator reports that some families will not admit that a family member has memory loss problems and will not accept help. The coordinator encourages these families to accept general support through other program services, such as meals and home care, but tries to educate the family to accept dementia-specific help before a crisis occurs. Trained volunteers providing families with other services from this Living at Home/Block Nurse Program also inform staff when they observe any of the 10 warning signs. The Atwater program coordinator is also making contact directly with community residents, relying largely on personal referrals and information from volunteers to locate individuals who may have memory loss problems.

Both Living at Home/Block Nurse Programs are encouraging local health clinics to institute dementia identification protocols. Although there are no medical clinics in Grove City, the Grove City Living at Home/Block Nurse Program coordinator has developed an informal relationship with the nearby Litchfield Allina and Affiliated Community Medical Centers clinics. The coordinator has met with Allina clinic staff and also with the nursing staff and hospice physician at Augustana Home Care to distribute memory loss folders. She is also helping the Allina and Affiliated clinics to develop a dementia identification program. The Litchfield clinic is part of the Affiliated Community Medical Center system, and the program coordinator has also been able to hold discussions about dementia identification with the medical center system's Litchfield hospital.

The Atwater Living at Home/Block Nurse Program has also established a relationship with its local Affiliated Community Medical Centers' clinic. Medical system management has approved formal cooperation between the Atwater program and the clinic, and clinic staff and the physician are engaged in dementia identification activities. Both pilot projects are developing protocols with the clinics for dementia identification. The physician is also distributing the Alzheimer's Association Memory Loss folders to caregivers of patients with memory loss.

Memory Disorders Clinic Partnership Pilot. The Central Minnesota Memory Disorders Clinic in St. Cloud provides training in dementia identification to the staff of the Health Partners clinic where it is located. Health Partners, one of Minnesota's largest integrated health systems, provides free space to the Memory Disorders clinic. Pilot project staff also have provided dementia identification training to nearby Centra Care hospital and its affiliated

outpatient clinics. Additionally, clinic staff have provided training on dementia to professionals, including several senior organizations and most of the independent clinics in central Minnesota. The clinic receives referrals from clinics throughout central Minnesota as well as self referrals.

Waseca Medical Center—Mayo Health System Faith-in-Action Memory Loss Partnership Pilot Project. This pilot project has concentrated its dementia identification efforts on individuals who come to Waseca Medical Center. Pilot program staff and the Waseca Medical Center neuropsychiatry clinic jointly developed a dementia identification screening tool. Two questions were added to the standard clinic Visit Information Form, which all patients visiting the Waseca clinic receive, one addressing memory loss and the other addressing caregivers of individuals with memory problems. Clinic patients responding "yes" to the first question, "Do you feel you have more problems with memory than most people your age?" receive further screening using the 10 warning signs of Alzheimer's; caregivers responding "yes" to the second question, "Do you often feel overwhelmed between caring for someone and trying to meet other responsibilities for your family, work, or yourself?" are further assessed by pilot program staff using a caregiver burden inventory. Patients identified with memory loss and heavily burdened caregivers are referred for further evaluation by their physician and the clinic's neuropsychologist.

Previously, pilot project staff had prepared a separate screening form. They provided the outpatient clinic with this form to distribute to all patients as a part of the clinic intake procedure. Pilot staff found, however, that patients were overwhelmed by the amount of information which was requested. Outpatient clinic staff also reported that patients often were offended by the form because they believed filling it out implied they had a mental problem.

Memory Loss Assessment and Diagnosis

The Chronic Care Networks for Alzheimer's Disease model calls for a rigorous formal assessment for people who have been identified with memory problems or other indicators of possible dementia. Not all persons with memory loss have dementia and not all memory loss is indicative of an illness. The model anticipates that two or three visits could be required to complete the assessment. Elements of the assessment include family interviews; functional, neurological, physical, and mental examinations; and a series of blood chemistry tests (Chronic Care Networks for Alzeheimer's Disease, 2003b). The grant is working to make assessment and diagnosis services available to medical clinics and community physicians and to ensure that physicians are better trained in conducting assessments.

The state is not directly engaged in memory loss assessment and diagnosis. All of the grant memory loss assessment and diagnosis activities are being conducted by the pilot sites.

Pilot Site Activities

The pilot sites are engaged in a range of activities to comprehensively assess and diagnose persons identified as having memory loss. Three of the pilot projects are working with physicians and clinics to develop dementia assessment and diagnosis capability either at general medical clinics or by referral to specialized dementia assessment facilities. These pilot projects are developing institutionalized pathways between medical and community providers for persons determined to have serious memory loss. While seeking to expand direct relationships with

medical providers, the pilot projects also are working directly with families. Their activities include conducting informal assessments and supporting families in seeking appropriate care from physicians and primary care clinics.

Three of the pilot projects use the Cognitive Performance Test as part of the assessment process. The Cognitive Performance Test is an evidence-based functional evaluation based on Allen's cognitive disability theory and used in occupational therapy evaluation. It measures overall brain activity based on activities of daily living, task performance, and the patient's ability to adapt to an environment (Katz, 1998). The test is also structured to allow the therapist to project the likely progression of disease symptoms and to advise the caregiver about what changes to anticipate in the client's behavior and abilities.

Because the test was designed to help predict client behavior, the Memory Disorders Clinic uses it to advise caregivers about strategies to help the client maintain independent functioning. The Cognitive Performance Test is used by the Payne-Phalen pilot project, and its staff have translated it into Spanish and Hmong. However, there are no validated versions of the Cognitive Performance Test in any languages other than English, and Payne-Phalen staff are working with staff from the Arrowhead pilot project and others to devise translations and adaptations of the Cognitive Performance Test which are culturally appropriate.

Arrowhead Dementia Identification and Care Companion Pilot. The Arrowhead pilot project in the Duluth region developed dementia assessment clinic services under the first ADDGS grant, establishing the St. Mary's/Duluth Clinic Memory Assessment Clinic. The original team included a geriatrician, social worker, occupational therapist, and nurse practitioner. The clinic conducts a comprehensive evaluation of the patient's physical, functional, social, and cognitive skills, using standardized tests such as the Mini-Mental Status Examination and the Geriatric Depression Scale. The clinic also performs nutritional testing and blood analyses. Along with reporting its findings to the patient and the patient's primary care physician, the clinic helps families access community supports and educational materials about Alzheimer's disease. Although the clinic no longer has a geriatrician on staff, it continues to perform overall geriatric evaluations.

Under the Working Together grant, the Arrowhead pilot program has concentrated on developing dementia assessment capability in rural clinics. Pilot project staff have provided training to seven clinics on dementia basics and communication tips for working with persons with dementia. Publicly funded caregiver coaches are invited to these sessions to familiarize clinic staff with these local resources for caregiver support. The pilot project has focused on developing dementia assessment capability among medical providers at the Gateway Clinic in Moose Lake/Cromwell, Riverview Health Care in Aitkin, and the SMDC clinic in Ely. The newly funded Community Services/Service Development grant to the Arrowhead Area Agency on Aging will support the development of additional dementia assessment capabilities in northeast Minnesota, including Duluth.

Bridge Partnership Memory Loss Pilot. The Payne-Phalen Living at Home/Block Nurse Program has a direct relationship for assessment and diagnosis with the HealthEast Salud Integral clinic, which serves the Hispanic community. For clients receiving care elsewhere, pilot project staff encourage and assist their clients in receiving these services. When families release

information to grant staff members, the project staff assist clients in scheduling assessments. Staff also help the families apply for Medicaid or Medicare to pay for assessment, if the client is eligible. Out of 265 clients served by the Living at Home/Block Nurse Program, 45 have received a medical diagnosis of memory loss, although pilot staff believe that many other clients have undiagnosed memory problems.

Staff members report that diagnoses are very difficult to obtain for Hispanic and Hmong clients, in part due to the lack of culturally appropriate assessment instruments. One way in which pilot staff have been able to assist Hispanic clients is by administering the Cognitive Performance Test in Spanish. They are able to do this because one Payne-Phalen staff member has appropriate training, previously having been a physician in Venezuela. The pilot is developing a protocol to send the test results to a client's physician.

Kandi-Meeker Cash and Counseling Memory Loss Pilot Project. Both the Atwater and Grove City coordinators are in discussions with their local clinics, encouraging them to develop a capacity for assessment and diagnosis of Alzheimer's disease and helping them to develop protocols for dementia assessment and diagnosis. The Grove City coordinator has met with staff from the Allina clinic in Litchfield and with the nursing staff and hospice physician at Augustana Home Care, also in Litchfield. The Atwater coordinator has developed an informal system of referrals through the doctor at the Affiliated Community Medical Centers clinic and has conducted training with the physician and staff.

Memory Disorders Clinic Partnership Pilot Project. The major function of this project is to provide assessment and diagnosis services through the Central Minnesota Memory Disorders Clinic in St. Cloud. It conducts an interdisciplinary assessment and provides physicians, patients, and patient families with test results, assessment reports, and follow-up services. The clinic's physical location at Health Partners has given it high visibility and credibility in the local medical community.

The interdisciplinary assessment process involves two visits to the clinic for physical, psychosocial, and functional assessment conducted by a social worker, an occupational therapist, and a nurse practitioner. Testing includes the Mini Mental Status Exam, the Cognitive Performance Test, the Geriatric Depression Scale, and the Neuropsychiatric Inventory Questionnaire. After these examinations, the assessment team meets with the clinic medical director to discuss findings and develop recommendations. The client, physician, and family/ caregiver receive a consultation report with recommendations to the client's primary physician for further testing or treatment, if appropriate.

The clinic is expanding the dementia assessment and diagnosis capacity of the overall health system through the assessment reports it sends to primary care doctors, which indirectly educate the physicians about dementia. The patient reports generated by the clinic include a description of the assessment process, including the tests and procedures used by clinic staff. By following the procedures and using the tests described in the report, the physicians who receive these reports have learned to conduct routine diagnoses for Alzheimer's disease and other memory loss conditions. With primary care physicians better able to provide patient assessment, the clinic may become primarily a resource for complex cases, including those requiring the

differentiation of vascular versus mental illness. At present, however, the clinic continues to accept all the referrals it receives.

Waseca Medical Center—Mayo Health System Faith-in-Action Memory Loss Partnership Pilot. Patients identified with memory loss by the dementia identification protocol developed by the pilot project and the clinic at Waseca Medical Center are referred to the medical center's neuropsychologist for assessment. Patients diagnosed with memory loss by the psychologist are referred for medical and therapeutic intervention, including medication, physical therapy, or occupational therapy, if appropriate. Families experiencing caregiver burden are connected to the clinic's caregiver coach.

Joint Care Management

In the Chronic Care Networks for Alzheimer's Disease model, joint care management is a key element. Once individuals with dementia are identified and clinically assessed, care plans to support the clients and their caregivers need to be established. The model calls for involving community support agencies as well as medical providers in a comprehensive approach to care (Chronic Care Networks for Alzheimer's Disease, 2003a). This differs from other models where the care management is either entirely acute care/medical or social/long-term care in its approach. The model identifies six domains of care management for patients diagnosed with Alzheimer's disease: patient function, caregiver support, medical care, psychosocial function, patient nutrition, and planning for advance directives (Chronic Care Networks for Alzheimer's Disease, 2003b). All of the grant activities in this area are being conducted by the pilot sites.

Pilot Site Activities

The pilot sites are cooperating with medical providers to provide care management based on an assessment of caregiver and client strengths, needs, and available community resources. Some of the pilot sites have established formal links to medical facilities and are working directly with medical clinic staff to provide joint care management. Pilot sites that are still formalizing direct clinic relationships are working with families to implement and supplement clinic care management plans.

Those pilot sites with formal links to medical facilities have developed protocols for care management. For example, the Memory Disorders Clinic pilot provides patients with a detailed care plan and coordinates the activities of community service providers to carry it out. The Waseca pilot participates in a joint plan with Waseca Medical Center, and takes responsibility for community care services. The Arrowhead pilot is employing a system of care consultants based in medical clinics who provide coordination between clinic care management planning and community service providers. The Payne-Phalen pilot refers Hispanic patients with dementia to the Health East Salud Integral clinic for joint care planning.

Those pilot sites without direct clinic relationships assist their clients in following the care plan of the medical provider. After the client receives a care plan from the medical provider, pilot staff review the plan with the client. The pilot project then locates or provides the support services which are specified in the plan. Staff provide counseling to help families understand the issues related to memory loss, how to relate effectively to medical personnel, and how to

understand tests and diagnoses. With a signed release from the client, pilot staff can also provide information to the physician and clinic.

The Working Together project calls this approach "parallel play," which it defines as activities by which community care networks support patients in following care plans provided by physicians, clinics, or hospitals, but where the staff do not have direct communication with the medical provider. The community care organization receives information about the diagnosis and care plan from the patient or the family, and then works directly with the patient and caregiver. Communication between the project staff and medical providers is through the caregivers or person with memory loss rather than directly between project staff and physicians. While not the optimal approach, it provides the community care organization with opportunities to support clients. The effectiveness of the approach, however, is dependent on the information provided by the caregiver or person with dementia. The parallel play approach works best when the caregiver/person with dementia team is willing and capable of managing the care plan and the community care organization serves as a care coach.

Arrowhead Dementia Identification and Care Companion Pilot Project. The Arrowhead pilot project provides direct care consultation services to assist persons with dementia and their families with care management. The project advocates a team approach to care management. In working with clinics through this approach, the pilot project hopes to build information-sharing pathways between the medical clinics and community care providers.

With Community Services/Service Development grant funding, the pilot project is providing caregiver coach services at the St. Mary's/Duluth Clinic Health System in Ely. This coach, working with the Alzheimer's Association and the Ely clinic manager, is arranging for dementia training for clinic staff about the role of the caregiver coach. The pilot has also approached other clinics about providing on-site care consultant coaching. Additionally, a grant-sponsored care consultant from the Alzheimer's Association is contacting Duluth clinics to explain the availability of the care consultation service. The newly funded Community Services/Service Development grant to the Arrowhead Area Agency on Aging will support the development of further joint care coordination capabilities in northeast Minnesota, including Duluth.

Bridge Partnership Memory Loss Pilot Project. The Payne-Phalen Living at Home/ Block Nurse Program works with the Health East Salud Integral medical clinic to provide joint care management. Project staff work directly with people with dementia and their informal caregivers to obtain needed services in other clinics as well. The pilot project uses the approach outlined in ***Appendix 4*** to guide the handling of referrals and in linking clients with medical care and appropriate services, such as respite care, and for follow-up by the project.

Kandi-Meeker Cash and Counseling Memory Loss Pilot. The Atwater and Grove City Living at Home/Block Nurse Programs are developing protocols for joint care planning with their area medical clinics. At the time of the site visit, they were providing care management to clients with dementia and their families without directly contacting medical providers.

The Atwater Living at Home/Block Nurse Program is seeking a closer clinic relationship, including joint care management, through discussions with Affiliated Community Medical

Centers, the parent corporation of the medical clinic in the community. The Grove City Living at Home/Block Nurse Program is in discussions with the Affiliated Community Medical Centers clinic and the Allina clinic in the neighboring community.

Memory Disorders Clinic Partnership Pilot. The Central Minnesota Memory Disorders Clinic provides community care plans to clients whom the clinic has diagnosed with Alzheimer's disease or another dementia. The care plan, which classifies patients according to care need levels ranging from those patients requiring no caregiver assistance to those requiring total care, identifies agencies and contacts to provide community supports. The care plan also includes information about advance directives and details a caregiving emergency backup plan. The care plan template and the six levels of care can be found in ***Appendix 5***. The clinic provides coordination of the services identified in the community care plan, follows up with the caregiver and the community providers identified in the plan, tracks insurance or Medicaid coverage, and provides education and support groups. The patient's primary care doctor and all community providers recommended in the care plan receive a copy of the plan. The clinic also provides community providers with a functional maintenance plan, a separate report dictated by the clinic nurse practitioner who details the patient's condition and needs.

Clinic staff follow up with the client and caregiver every 3 to 6 months to monitor the patient's condition and report the findings to the doctor. These reports are generally written, but the clinic telephones the physician in urgent cases. The clinic receives feedback from physicians through copies of their notes for patients' charts.

Waseca Medical Center—Mayo Health System Volunteers-in-Action Memory Loss Partnership Pilot Project. The pilot project staff and the Waseca Medical Center clinic have jointly implemented a case coordination strategy for clinic patients. The hospital social worker assists patients while in the hospital, and the pilot project caregiver educator follows them after hospital discharge. The pilot project caregiver coach continues to monitor patients for up to a year, or longer as required, checking with families once or twice a month. The pilot is also engaged in developing a wider community capacity for care management through the caregiver coach who works with county long-term care consultants,[3] community service providers, and physicians to coordinate community services and medical care.

Training and Support

The fourth major element of the Chronic Care Networks for Alzheimer's Disease approach is to provide training and support to caregivers throughout the six phases of caregiving—prediagnostic, diagnostic, role change, chronic caregiving, transition to alternative care, and end of life. Throughout these six phases, the model prescribes a menu of activities, which include providing basic information, counseling, and support groups (Chronic Care Networks for Alzheimer's Disease, 2003b). The Working Together statewide effort includes education for providers, families, and clients and also social supports for families. The pilot sites are focused on providing both formal and informal caregivers with education about and links to services, coaching, support groups, respite, and other needed supports.

[3] Minnesota county long-term care consultants are county public health nurses or social workers who help clients identify and access services.

Statewide Initiatives

The statewide training initiatives of the ADDGS project include educational opportunities for both formal and informal caregivers. For formal caregivers, the grant has cooperated with the Alzheimer's Association Chapter to produce Memory Loss Care, a four-part video conference series about Alzheimer's disease. Formal and informal caregivers are offered the 1-day dementia care course and other educational programs. The four-part Memory Loss Care video conference series was developed with the Alzheimer's Association Chapter and offered with the support of the state Department of Human Services' Real Choice Systems Change grant. The 4, 2-hour videoconference sessions on Alzheimer's disease were presented at 30 locations in rural and urban settings around the state. Most attendees were county public health nurses, social workers, and staff from community-based services, health plans, and nursing homes. The presentations educated participants about the early warning signs of dementia, the process and benefits of getting a diagnosis, common behavioral concerns and treatment options, and strategies for supporting family members. Participants were encouraged to network at the sessions and time was allowed for participants to make presentations about their work in Alzheimer's care.

ADDGS grant staff distributed videotapes of the conferences to each of the state's 87 counties, Area Agencies on Aging, and health plans. Copies of the videotapes are available from the Alzheimer's Association Chapter and its regional offices, along with supporting educational material about the Chronic Care Networks for Alzheimer's Disease approach and ADDGS project instruments and protocols. The Alzheimer's Association Chapter established a certificate program for people who complete the course at the original presentation or from viewing the tapes.

The four Memory Loss Care videoconferences were well attended, with 314 participants. In a follow-up survey of attendees, 29 percent of participants indicated a greater understanding of the 10 warning signs of Alzheimer's disease, 25 percent either offered or referred clients to Savvy Caregiver training, 21 percent reported increasing their referrals to physicians, 33 percent reported increased referrals to the Alzheimer's Association Chapter, and 26 percent indicated they were developing more caregiver support plans.

The Working Together grant and the Alzheimer's Association Chapter are also offering a "Dementia 101" training program, which was developed under the first grant. This program is intended for advocates of people with dementia, particularly parish nurse and faith-in-action projects whose volunteers serve those with dementia. A respite volunteer training curriculum, also developed by the first ADDGS grant, has been presented to nearly 1,000 volunteers. The Alzheimer's Association provides the Savvy Caregiver training program, with adaptations developed in cooperation with Kenneth Hepburn, Ph.D., the author of the program (Hepburn, 2006). With ADDGS grant support, the program is offered at no cost to caregivers. The Alzheimer's Association also offers the "Partnering with your Doctor" curriculum to educate informal caregivers about participating in the assessment and diagnosis process. In addition to these other programs, the Alzheimer's Association makes available an array of educational presentations about early identification, memory loss, Alzheimer's disease and developmental disabilities, financial and legal planning, and activities-based care for people with Alzheimer's disease.

For its major statewide support initiative, the grant is working with the state Aging and Adult Services Division of the Department of Human Services to enhance state support for caregivers through a new network of dementia-competent "caregiver coaches." The coaches will be highly trained care managers who will work with caregivers. The role of these coaches will be to help caregivers define reasonable goals, provide structure for caregivers as they pursue those goals, and provide personal support for caregivers. Typical activities will be assisting caregivers in defining their information needs, helping caregivers to develop a support network, and helping caregivers to make decisions that will enhance their lives.

The standards for the training and qualifications required of these coaches are under development. ADDGS grant and Department of Human Services staff agree, however, that these individuals need to be proficient in counseling and family dynamics and experienced in social work or a related field. They will also need to be culturally competent and knowledgeable about chronic illnesses and long-term care. Because the term "coach" is commonly used and unregulated, planners believe that a certification program is necessary to differentiate these highly trained professionals. The Department of Human Services anticipates an initial training class of 50 caregiver coaches, with an ultimate goal of having at least one coach in every county.

The Working Together ADDGS project is making other information and tools available to caregivers online through the Memory Care Web site maintained by the Minnesota Board on Aging. The Web site, at www.mnagingproviders.org/memorycare/, provides memory loss identification tools and protocols, assessment and care management tools, physician guidelines, group respite information, and other useful information about Alzheimer's disease and support materials for families and professional caregivers. Among the tools on the Web site is a memory loss questionnaire which is based on early identification tools developed under the Chronic Care Networks for Alzheimer's Disease demonstration. The questionnaire can be used by caregivers to identify long-term care needs of older adults, identify community services, create a care plan, and request personalized assistance. Also on the Web site are materials to support respite activities, including instructions for creating the Joy Kits of simple activity materials for use by individuals with Alzheimer's disease developed under the first ADDGS grant. The Web site includes links to the Savvy Caregiver education program, materials about the Chronic Care Networks for Alzheimer's Disease approach, and a description of the ADDGS grant statewide and pilot project efforts.

Pilot Site Activities

All the pilot projects of the ADDGS project are providing educational opportunities for both formal and informal caregivers. Pilot staff members are providing group presentations and one-on-one training to professional staff. The pilot projects are also working with clients individually to educate them about Alzheimer's disease and the service options available to them. All of the pilot projects are offering supports to caregivers, including respite, transportation, support groups, and chore services. One pilot, the Kandi-Meeker project, is implementing a Cash and Counseling caregiver support program.

Arrowhead Dementia Identification and Care Companion Pilot Project. The Arrowhead pilot provides training for staff from community services, county long-term care providers, parish nurse agencies, faith-based support services, residential service providers, and

health care organizations about the basics of Alzheimer's disease and the community services available to help individuals with dementia and their families. The pilot project provides education for family caregivers through classes such as Savvy Caregiver. It also provides care consultation and coaching services though a grant-funded position at the Alzheimer's Association office. Other caregiver coaches, funded by the Arrowhead Area Agency on Aging under Title III-E of the Older Americans Act or by the state Community Services/Service Development program, are available to provide education and support to family caregivers of clinic patients.

The Arrowhead pilot directs clients and families to respite care, a service that was begun under the first ADDGS grant. Two of the three respite programs originally funded under the first ADDGS grant still continue to service caregivers of persons with dementia. One of the programs, in Carlton County, is volunteer based. It offers both in-home and group respite, and the group respite service has experienced a significant increase in use by caregivers of persons with dementia in the past year. The second program, based in Itasca County, provides consumer-directed respite care to families through ElderCircle Respite Services. ElderCircle serves as the employer of record for paid respite workers who are selected and managed by family caregivers. In 2005, the ElderCircle program provided about 1,500 hours of paid respite to 15 family caregivers, with about 60 percent of those services provided to families coping with dementia.

The newly funded Community Services/Service Development grant to the Arrowhead Area Agency on Aging will also support the development of additional caregiver and support capabilities.

Bridge Partnership Memory Loss Pilot. The Bridge Partnership pilot has established an educational program through which student nurses and resident physicians gain experience while serving caregivers. The student nurses and resident physicians are trained in early dementia identification, assessment, and care coaching, and provide individualized coaching to caregivers in the community. They also provide some respite care services.

Payne-Phalen staff also provide training to local clinics and hospitals in east St. Paul, educating nurses, social workers, and other staff about the Block Nurse Program and other Alzheimer's disease resources. The health educator makes presentations to medical professionals and to community members, both in groups and one on one. Pilot staff distribute the Alzheimer's Association Chapter-produced "Memory Loss" packet to clinics, clients, healthcare providers, physicians, and volunteers.

By respecting cultural norms pilot staff are able to establish relationships with clients that allow the staff to educate families about memory loss and provide supportive services. For instance, pilot staff have learned that Hispanic clients are hesitant to admit that a family member has Alzheimer's disease because it is equated with mental illness in their community. By adopting the family practice of speaking of the person as forgetful, pilot staff members are able to help the family acknowledge the problem and accept assistance.

Pilot project staff report other beliefs and cultural attitudes affecting ethnic communities. For example, Hispanic adult children are extremely reluctant to tell their parents what to do because to do so would be disrespectful. Additionally, because of the language barrier, Hispanic

elders may refuse to travel with anyone who does not speak Spanish because they are afraid of not being able to communicate with the person if there is a problem, limiting who can volunteer to provide transportation services. Pilot project staff report that both Hispanic and Hmong populations have difficulty with the concept of long-term drug therapy for chronic illnesses, expecting a short-term course of treatment to solve the problem, and hence are likely not to continue maintenance medication without ongoing encouragement and monitoring. Pilot project staff related that some members of both communities believe that to speak about a disease is to make it happen, making attendance at education sessions difficult. Pilot project staff members report that respect for these views and the development of a trusting relationship is essential for them to serve these communities.

Community education and support groups are organized in Spanish and Hmong, although many caregivers are unable to arrange respite to attend. There is also a biweekly gathering for Hispanic elders with memory loss, which provides respite for their informal caregivers. Volunteers provide rides to medical appointments and grocery shopping, and serve as friendly visitors to support caregivers. The pilot project can bring in personal care and homemaker services as needed. Most of the clients served by the pilot project are poor, and the pilot seeks reimbursement through the client's insurance or Medicaid when the client is eligible.

Kandi-Meeker Cash and Counseling Memory Loss Pilot. The Atwater and Grove City Living at Home/Block Nurse programs provide Cash and Counseling as well as more traditional support services. The two sites work with the Elderberry Institute to offer Cash and Counseling, which is a type of consumer-directed service in which clients have flexible budgets that can be used to purchase a wide range of services. Consumers can hire their own workers, who are often their friends and relatives.

Consumer-directed home care has been available to some individuals in Minnesota since 1998, and was expanded statewide in 2005 for participants in the Medicaid Home and Community-Based Services waiver and the state Alternative Care Program. The Minnesota Board on Aging has approved policy guidance for the development of consumer-directed Older Americans Act Title III-funded services. Additionally, Minnesota was awarded a Robert Wood Johnson Foundation Cash and Counseling Grant on October 1, 2004, to support the creation of permanent, multi-point, statewide access to a consumer-directed option for older adults and younger disabled adults with physical disabilities.

The Atwater and Grove City programs identify and support clients eligible for Cash and Counseling, while the Elderberry Institute provides fiscal agent services such as withholding taxes and paying workers. Clients cannot pay providers more than state payment rates. Paid services as well as volunteer assistance are available to the family. Volunteers are identified and assigned by the Living at Home/Block Nurse Program, while the client is responsible for identifying, hiring, and supervising a paid assistant. At the time of the site visit, the pilot project was just beginning its Cash and Counseling program.

The Atwater and Grove City Living at Home/Block Nurse Programs also provide training classes and informational programs for formal and informal caregivers. The Grove City pilot holds training sessions for provider staff from local hospitals, clinics, and health care agencies, and works directly with nursing providers serving families with dementia. The Grove City pilot

also holds an annual Health Expo and distributes information at the Meeker County Fair. The programs also agreed to recruit an additional five volunteers during the project for training to provide caregiver support. Each program maintains current listings of community resources to assist individuals with Alzheimer's disease and their families, and to publicize these resources through outreach activities.

Both sites provide a range of services for caregivers, including volunteer respite, home health care, personal care, adult day care, and coaching services. Specific activities conducted by the sites include support groups, connecting families to respite services, and holding community Alzheimer's educational events. These two sites are also distributing Joy Kits.

Memory Disorders Clinic Partnership Pilot. The Memory Disorders Clinic offers a memory disorders support group that meets monthly. Both caregivers and care receivers meet together for an hour before meeting separately for an hour at each session. This provides an opportunity for social interaction before the caregivers discuss their experiences. Faith-in-Action volunteers support caregivers through the pilot project by providing personal care, care companion, and respite care services.

Waseca Medical Center—Mayo Health System Faith-in-Action Memory Loss Partnership Pilot. Waseca Medical Center provides ongoing training of hospital and clinic staff and physicians. It introduced the Alzheimer's Association Chapter-produced Memory Loss folder to the clinic, which is now among the standard clinic resources used by physicians to educate patients.

Services are provided to caregivers by a caregiver coach/educator. The coach/educator also trains community service providers and works directly with caregivers, providing educational materials and caregiver coaching, and helping to identify available services.

Caregivers also receive support from the pilot Volunteers-in-Action program. Caregivers identified by the clinic sign a release of information form/request to participate in the program. When this permission is granted, volunteers contact the caregivers and make arrangements to provide them with support in the home, including help with chores, support from the Lifeline Emergency Response system, and social visits. The pilot project also provides support for caregivers through volunteer respite, grief support, support groups, and personal and group educational opportunities.

SECTION 5
GRANT STRATEGIES FOR SYSTEMS CHANGE AND SUSTAINABILITY

Both of the Alzheimer's Disease Demonstration Grants to States (ADDGS) grants have sought to promote systems change and to sustain their activities at the end of the grant funding. The first ADDGS grant worked to improve the effectiveness and responsiveness of the state home and community-based network of services, and instituted a number of pilot service programs. The continuation of its efforts with the first grant was achieved largely by integrating grant activities into ongoing operations of the Alzheimer's Association Chapter, and through a combination of local, state, federal, and private funding. The second ADDGS grant, which is ongoing, is focused on embedding dementia competency into existing systems and developing a statewide network of relationships linking health care and community support organizations. In this way, activities of the second ADDGS grant can be sustained as a part of the larger state health and long-term care system.

Minnesota Alzheimer's Demonstration Project Activities

Statewide dementia education activities conducted under the first ADDGS grant reached a large audience, with more than 12,000 providers, volunteers, families, and others attending its educational programs. A respite volunteer curriculum was presented to nearly 1,000 volunteers, and the "Black Clouds, Sunny Days" depression awareness campaign was directed to the general public, with over 70,000 consumer brochures and other materials distributed. Training for volunteer caregivers was provided by the Alzheimer's Association Chapter, and has continued under the second grant. The Alzheimer's Association experienced a 30 percent increase in calls to its help line over the 4 years of the first grant. Although there is no way to know what part of this change is due to project initiatives, grant staff believe that these activities created a growing awareness of Alzheimer's disease.

The major services implemented under the pilot programs of the first grant were respite and adult day care supports. These grant activities primarily expanded the overall availability of these services and introduced them into communities where they had not previously been available. Some of the adult day care and respite efforts introduced under the grant have been continued with the support of the Older Americans Act Title III-E National Family Caregiver Support Program. Volunteer respite services developed by pilot projects implemented under Living at Home/Block Nurse programs are continuing without additional funding.

Another aspect of the first ADDGS grant was the development of a memory assessment clinic at St. Mary's hospital in Duluth. Since the end of the grant, clinic operations have continued under the management of the hospital.

Working Together Grant Statewide Initiatives

Although the Working Together grant is still operating, grant staff are working closely with the state Department of Human Services and the Minnesota Board on Aging to integrate the accomplishments of the grant into ongoing state activities. Under the Memory Care Initiative, the creation of a statewide dementia-capable long-term care system is part of the State Board of Aging's core mission. Grant dementia care activities are being linked with the programs of the Aging and Disability Resource Center and the Community Services/Service Development

program. The Minnesota Board on Aging has developed partnerships with the agencies within the Department of Human Services, the Alzheimer's Association Chapter, and health care and community care organizations across the state. The Minnesota Board on Aging is also making an array of tools for memory loss identification, assessment, care management, and education available through the Memory Care Web site. State Department of Human Services agencies and programs, including the Senior LinkAge Line™, the Aging and Disability Resource Center, and the state consumer-directed home care program, have agreed to embed dementia capacity into their services. The MinnesotaHelp.Info database, which tracks the activities of the Senior LinkAge Line™, has been revised so that it now tracks the dementia referrals. Community Services/Service Development funding, which the current project has leveraged to expand the reach of its dementia initiatives, is expected to continue to fund grant pilot projects partially funded by the ADDGS grant.

Other support for continuing grant activities may come from outside state government. Grant management has held discussions with the Robert Wood Johnson Foundation and the Bader Foundation for support of activities after the conclusion of the present grant. The educational efforts which the Alzheimer's Association's Chapter has contributed to ADDGS grant activities will continue to be implemented as a part of its core mission at the conclusion of the grant, to the extent that its funding allows. As an experienced nonprofit organization, the Alzheimer's Association's Chapter has a diverse mix of funding sources, including grants and contracts with Area Agencies on Aging.

Working Together Grant Pilot Projects

After the conclusion of grant funding, leaders of the current ADDGS grant expect grant activities to continue to have an impact because they have been embedded in the organizations which implemented the pilot projects. All the community organizations at the sites provided client services before their involvement with the grant, and the practices and relationships developed by the pilot projects are becoming part of their regular procedures.

The community organizations that implemented the pilot projects will likely continue to function after the end of the grant. Some of the pilot sites receive substantial Community Services/Service Development grant funding which will help these organizations to continue operation. The continued role of dementia competency within these sites will, however, depend on each site's perception that this competency advances the organization's overall mission. Grant staff are working with each of the pilot projects to maintain their focus on continued dementia-competent operations after grant support has ended.

Individual pilot projects have specific plans for continuation:

- The Arrowhead pilot project reports that its efforts will continue through the dementia identification training provided by the Alzheimer's Association Chapter. The project also anticipates that the dementia identification, assessment, and care coordination strategies will become institutionalized at the host clinics.

- Payne-Phalen is working with the EverCare and HealthEast health systems to gain reimbursement for its dementia services to its patients with memory loss.

- The Kandi-Meeker sites are Living at Home/Block Nurse Programs with experience in local fundraising, which may support their activities. They also expect that the Medicaid home and community-based services waiver will provide some funding. They hope to gain support from the local clinics, as well. The dementia expertise being developed by the Living at Home/Block Nurse Program coordinators will continue to be available at the conclusion of the grant.

- The Memory Disorders Clinic in St. Cloud has secured some reimbursement from Medicare and Health Partners, and is continuing to work with other medical providers and insurance companies to establish payments for their services. Reimbursement is currently hampered by the lack of a paid medical director, however. The present director is a volunteer, and Blue Cross will not cover clinic services without a paid medical director. Because there are no plans at present to engage a paid director, this may continue to limit reimbursement. Reimbursement for social work is also an ongoing issue because diagnostic and service coordination activities are not reimbursable, although counseling therapy is. The main sources of funding for the clinic are the Community Services/Service Development grant program and the Central Minnesota Council on Aging using Older Americans Act money.

- The Waseca pilot project, because of its integration with the hospital system, has access to funding from the hospital's development department. The Waseca Volunteers-in-Action project is affiliated with Project ROSE (Reaching Out to Support Elders), a regional Caregiver Support and Respite Program of the Minnesota River Area Agency on Aging, which is funded through a Community Services/ Service Development program grant.

Additionally, the Elderberry Institute has received a foundation grant on Cash and Counseling, which will be matched with state funds, to help with the development and implementation of a consumer direction project.

SECTION 6
CONCLUSION

The Minnesota Alzheimer's Disease Demonstration Grants to States (ADDGS) grant projects have developed a broad range of approaches to the problem of memory loss both statewide and in rural and urban settings across the state by applying the principles of the Chronic Care Networks for Alzheimer's Disease model:

- *dementia identification*, including linkage to both medical and social care resources;
- *memory loss assessment and diagnosis*, recognizing the critical role played by the physician and the medical care team in patient care;
- *joint care management*, in which the patient's care is coordinated by a team of medical and social providers; and
- *training and support services*, combining and coordinating the education of providers, families, and clients with social care support for the entire family.

The Chronic Care Networks for Alzheimer's Disease model provides a strong conceptual framework to organize the activities of the grants, giving then a unifying theme and way to fit the pieces together. The Minnesota projects are relatively unique among ADDGS grants in their focus on the health and long-term care systems, rather than on the long-term care system alone.

The Minnesota ADDGS grants have implemented these principles through partnerships with a range of organizations. At the state level, the grants integrated their efforts with the state Community Services/Service Development grant program and other units of the Department of Human Services and worked closely with the Alzheimer's Association Chapter. Through partnership with the Elderberry Institute, the grant aligned its efforts with state Living at Home/ Block Nurse programs. At the local level, these Living at Home/Block Nurse programs, Area Agencies on Aging, and Faith-in-Action projects make community and clinical services available to persons with memory loss and their families.

In the area of dementia identification, the project has increased awareness of Alzheimer's disease on a statewide level and in selected rural and urban communities. The Senior LinkAge Line™ now identifies seniors with memory loss and caregivers in need of support. The community outreach activities and clinic-based identification systems developed by the pilot projects offer useful models for replication by other community-based and medical organizations.

The project has developed assessment and diagnosis services in hospitals and medical clinics. The Memory Disorders Clinic, in particular, has established the viability of an assessment clinic relying primarily on nursing, occupational therapy, and social work evaluation, and the model has gained acceptance in the local medical community.

The project has effectively developed care management models through direct cooperation between the pilot projects and medical clinics, developing protocols and pathways for patient management within the medical system. The pilot projects have also developed a

process to help patients and caregivers to implement their clinical care plans when no direct cooperation is in place between community service agencies and medical providers. Through the "parallel play" approach, the pilot projects help the family follow the clinical care plan.

The project has instituted educational programs at the statewide level, particularly the videoconferences and videotaped presentations available for ongoing instruction. Discussions are underway for certification for caregiver coaches. The project has also equipped local pilot projects with materials which have educated providers and families about available support services.

Working through five pilot projects, the Working Together grant has demonstrated initiatives that address issues of rural and urban settings. In the rural setting, the grant faced a limited supply of services. Pilot projects filled this gap by training and using volunteers for caregiver support. Moreover, some rural physicians were unaware of how to conduct a basic Alzheimer's disease assessment, and the pilot Memory Disorders Clinic has become a resource for them through its assessment reports. Pilot projects in rural areas discovered that people were reluctant to admit to memory loss problems, and the pilot projects worked with these individuals and families to provide them with social and educational support. In general, pilot projects in rural areas found that it was essential to establish a trusting relationship before being able to provide support.

The urban Bridge Partnership pilot demonstrated the effectiveness of the Chronic Care Networks for Alzheimer's Disease model in addressing issues related to the multi-ethnic communities. Several cultural factors were identified by pilot project staff, including how adult children interact with older people in Hispanic communities and the importance of being able to speak the language in order to provide support. Another issue the pilot project encountered is that Hispanic and Hmong communities are resistant to the notion of long-term medication therapy, expecting that short-term drug treatment will solve the problem. As in rural areas, a key finding reported by pilot project staff report is that the development of a personal relationship is essential to assisting members of these communities.

The Working Together ADDGS grant project has structured its activities to promote sustainability and systems change. Through its partnerships with major state programs such as the Senior LinkAge Line™ and the state Community Services/Service Development grant program, the grant project has made Alzheimer's disease awareness a part of ongoing state programs that provide health care information and service to the public. At the local level, pilot projects have established working relationships between medical providers and community service agencies. Pilot projects have established memory loss assessment services and introduced Alzheimer's disease awareness into the everyday operations of ongoing community service providers.

The Minnesota ADDGS grant projects have demonstrated the value of the Chronic Care Networks for Alzheimer's Disease model in addressing the needs of persons with dementia and their families. Project activities have applied the model through activities at the state level and at urban and rural local sites. The project has also provided a statewide organizing structure to bring expertise to local settings. Project activities have identified an increasing number of individuals with Alzheimer's disease, and they and their families have been referred for services.

The grant has established a model for Alzheimer's disease assessment which can be used by social and medical providers. By developing direct links with medical providers, pilot projects have demonstrated the feasibility of developing protocols for joint care planning by providers in community long-term care and clinical settings. Through grant-funded educational efforts, care professionals across the state are more aware of Alzheimer's disease and are better equipped to assist patients and families. Statewide and pilot projects have also provided families with a range of needed support services. Project achievements are being integrated into the functions of ongoing organizations at the state and local levels. As part of the integrated approach of the Minnesota Board on Aging to providing care for the older population, the achievements of these projects will promote sustained systems change to enhance the lives of persons with Alzheimer's disease and their caregivers.

REFERENCES

Chronic Care Networks for Alzheimer's Disease (2003a). *A New Model for Dementia Care*. Available at http://www.nccconline.org/pdf/CCNAD_4-pager_7-03.pdf.

Chronic Care Networks for Alzheimer's Disease (2003b). *Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia*, available at http://www.nccconline.org/pdf/CCN-AD_tools6-03.pdf.

Chronic Care Networks for Alzheimer's Disease (Undated), *Year One Evaluation of the CCN/AD Project*, available at http://www.nccconline.org/members_pdf/bpl/alzheimers/YearOne.pdf.

Hepburn, K (2006). *Minnesota Alzheimer's Demonstration Projects Evaluation*. Minneapolis, MN: University of Minnesota School of Nursing.

Katz, N. (Ed.) (1998). *Cognition and Occupation in Rehabilitation: Cognitive Models for Intervention in Occupational Therapy*. Bethesda, MD: American Occupational Therapy Association.

U.S. Administration on Aging (2006). Alzheimer's Demonstration Program Fact Sheet, available at http://www.aoa.gov/alz/public/alzabout/aoa_fact_sheet.asp.

APPENDIX 1
ROLES AND RESPONSIBILITIES OF ALZHEIMER'S DEMONSTRATION PROJECTS

1. Dementia (Memory Loss) Identification

A. Physicians/Clinics

i. **Engage** local **clinics** in working with you. Work with them to devise a strategy to include a memory loss question/10 warning signs in their patient intake questionnaire, give the family questionnaire to caregivers and give Memory Care packet to families with potential dementia.

ii. Work with the Alzheimer's Association to **educate clinic** staff, nurses, and physicians regarding your services, dementia identification, and strategies for referral and care coordination.

iii. **Establish ongoing working relationships for referrals and follow-up.** May establish office hours in the clinic for ease of referral, follow-up contacts, and care coordination.

B. Community Service Providers

i. Work with/educate community providers to **identify and refer people to you and the Alzheimer's Association** with possible dementia—using the 10 warning signs and other strategies. Encourage them to incorporate a memory loss question/10 warning signs in their intake/screening/assessment tool or process. Provide them with examples/templates (yours and others').

C. Your Organization

i. **Incorporate memory loss identification** (memory loss question/10 warning signs) **into your intake process**. Identify all people who come to you for possible memory loss.

ii. Develop and use a **release of information form (unless there is a reason not to).** You may refer clients for medical dementia assessment and treatment and receive information (engage in care coordination) as well as referring them to other providers and being able to coordinate care (receive and give information to each other updating you on the client's progress). Also obtain a release of information to give you permission to talk to other family members.

iii. Give the **family questionnaire** to caregivers.

iv. **Refer** people you have identified with possible dementia **to a/their physician** for a medical work up, diagnosis, and treatment **and** to the **Alzheimer's Association** for additional support.

2. Medical Assessment and Treatment

A. Work with the caregiver/care receiver team (c/c team) to **prepare for the doctor's visit.**

B. **Send a letter to the doctor with the signed release and then call the clinic** (or use whatever strategy you have agreed upon with the clinic to make referrals, the important thing is to get your information into the patient's file).

C. Use signed **release of information** to provide the physician/clinic with initial background information, **ongoing updates** on progress, negotiate release of information so that you may receive updates from the physician as well.

D. Care receiver receives medical workup, cognitive performance testing, diagnosis by physician, and treatment. Joint care planning begins.

E. **Engage in follow-up with the c/c team** to discuss and document the results of the clinic visits as well as ongoing.

F. **Build relationships/educate clinic staff** so that they know that effective treatment includes working with community providers on addressing behaviors and environment (outcome measures).
G. **Reach a written agreement on information sharing pathways.**

3. Care Management

A. Complete **an assets-based assessment of caregiver strengths** and what they **need**. Develop the care management plan referencing the disease phase the care receiver is in (Wayne Carron's model).
B. **Ensure** that **care management** with the person with dementia **has a central control** to eliminate care management plans that are fragmented. Work with the c/c team as first possible home for plan to whatever extent they have the capacity to do it—this will change over time and that is okay. **Engage in future planning with the c/c team** to anticipate what is coming and build it into the plan; the plan is very fluid. **Consult with the Alzheimer's Association caregiver consultants**, they are good at this part of plan development.
C. **Clarify the roles of everyone** involved—family, clinic, county, other community providers, volunteers, friends.
D. **Know your community providers**—make time to get to know everyone, especially if you or they are new.
E. **If** the **family** is **capable** of managing their **care plan**, the care plan should have its home with them.
F. **Educate clinics: Improved treatment outcomes result from integration of community care management plan and their treatment plan.** Develop a care management procedure with the clinics/physicians of your clients.
G. **Provide ongoing care management with the clinic and other community partners.**
   i. Develop a plan or strategy for care with the c/c team, clinic/physician, and agencies providing services.
   ii. Ensure that necessary release of information is in place to implement the plan.
   iii. Provide follow-up care coordination to carry out care management plan.

4. Caregiver Support and Education

A. Complete a **Caregiver Support Planning Tool** with your project partners to do community resource and gaps identification.
B. **Refer, arrange, or provide caregiver support services** as indicated in the plan.
C. **Provide or refer for one-on-one coaching** services to increase/improve skills and confidence (self-efficacy), reduce burden, and prolong length of time providing care.
D. **Provide caregiver education** activities—skills development, refer to event or training to provide support and increase knowledge (example: Savvy Caregiver).
E. **Support groups—peer support, mentor.**
F. **Identify and encourage natural supports**—ask who else could you talk to (a neighbor, someone at work, someone at church, a friend, relative or nurse).

February 28, 2006

APPENDIX 2
SENIOR LINKAGE LINE REFERRAL PROTOCOLS AND STEP-BY-STEP INSTRUCTIONS FOR REFERRAL CLIENT TRACKING FIELDS

Minnesota Senior Linkage Line® and the Alzheimer's Association Minnesota North Dakota Chapter Information Helpline

Purpose:

1. To ensure that accurate and thorough information about and referrals to the Alzheimer's Association Information Helpline for services for seniors with possible memory loss are provided.
2. To promote collaboration between the Alzheimer's Association Information Helpline (Information Helpline) and the Senior Linkage Line® (SLL)

Specialized Areas of Expertise
Both SLL and the Information Helpline recognize and understand that each Line has specific areas of expertise and knowledge that are not duplicative of each other.

The SLL areas of expertise are:

1. Referral to services and support resources throughout Minnesota
2. Medicare
3. Long-term care insurance
4. Prescription drug expense assistance
5. Forms assistance
6. Grandparents raising grandchildren
7. Caregiver planning, support, and training
8. Long-term support and referrals to county long-term care consultants for people age 60 and older

The Information Helpline areas of expertise are:
Memory loss information and resources:

1. Care Consultation
2. Family Education
3. Support Groups
4. Residential and Service Referral
5. Helpful Fact Sheets on a variety of dementia-related topics
6. Professional Education
7. Safe Return® Program
8. Community Education
9. Advocacy

Referral Protocols

General Principles

- The goal is to provide timely, accurate, comprehensive information and assistance to all callers with suspected memory loss no matter which Line they contact.
- The SLL and the Information Helpline will utilize the expertise of each other to ensure callers receive the best service possible.
- The services provided by the SLL and the Information Helpline are key components of long-term care reform in Minnesota. All assistance provided by the SLL; the Information Helpline embraces commitment to providing information and assistance to help promote independent living in the community.
- All calls that need to be transferred from one line to the other will adhere to protocols outlined below to ensure the caller does not have to repeat his story.
- Each Line will assess the needs of each caller. The SLL and the Information Helpline shall not automatically transfer a person to the SLL or Information Helpline without conducting an assessment and making the determination whether the expertise of SLL or the Information Helpline is needed. Examples include:
    - If a senior calls the SLL line and has a wide variety of issues including possible memory loss and/or already has a relationship with an SOS worker or a Caregiver Coach the call should not be transferred to the Information Helpline but recorded as a referral and given to the SOS worker or Caregiver Coach for follow-up. The SOS worker and Caregiver Coach may contact the Alzheimer's Association family care consultant for expert assistance on the issues relating to memory loss.
    - If a senior calls the Information Helpline and has issues that relate directly to memory loss and does not need other community support services the Information Helpline should handle the call and record it as a referral.

Referral Protocol 1

A caller will be transferred from one Line to another using the following protocol:

1. SLL or the Information Helpline has made the assessment that the caller needs the expertise offered by the other Line.
2. The caller will be informed that there is expertise available to help him and he can transfer his call to a staff person with the knowledge to assist him further. The caller will be given the option of having the call transferred directly to the other Line or receiving a phone number to call on his own.
3. In some cases where a strong relationship has already been established with the caller, and staff believe it would be detrimental to the caller to transfer the caller, the Line staff may also offer to call the other Line on his behalf and get back to him.
4. Before a call transfer occurs,
    a. Relevant data privacy and confidentiality issues will be discussed with the caller.
    b. The phone number of other Line shall be given to the caller in case the transfer is not made successfully.
5. When making the transfer to the other Line, staff will conduct the transfer in a manner that ensures excellent customer service.
6. Once the caller has indicated he wants to be transferred, the staff will put the caller on hold, conduct the transfer to the other Line and without the caller on the line, and give the

other Line staff a brief synopsis of the issues, including the caller's name and other identifying information.
7. Staff will introduce the caller to other Line staff completing the transfer and the other Line staff will remain on the line to ensure the transfer has been done successfully.
8. Both Lines will record the call in Referral.

Referral Protocol 2
A caller will be transferred from the Information Helpline to the SLL when the caller needs:

1. Assistance with completing forms for programs. Forms include: Medical Assistance application, Asset Assessments, MN Health Care Programs Application, Alternative Care Financial Determination, Medical Assistance Eligibility Re-determination/Renewal forms, Prescription Drug Patient assistance program forms.
2. Assistance related to Long-Term Care Insurance.
3. Assistance related to prescription drug coverage options.
4. Assistance related to Medicare and other health insurance questions.
5. Caregiver support services (if support is not dementia specific).
6. Assistance with raising a grandchild.
7. Assistance with identifying and reporting waste, fraud, and abuse in Medicare and Medical Assistance.
8. Assistance with locating long-term care services, including home and community-based services for people 60 and older.
9. Other in-depth senior resource information.
10. In-person assistance. The Senior Linkage Line® has staff and volunteers available statewide to provide in-person assistance with the areas of expertise noted above.

Referral Protocol 3
A caller will be transferred from the SLL to the Information Helpline when the caller needs memory loss-specific help including:

1. Advocacy
2. Care Consultation
3. Individual problem solving on behavioral issues, family meetings, and other areas which may be provided by phone or in person
4. Family Education
5. Support Groups
6. Residential and Service Referral
7. Safe Return Program
8. Books
9. Video Lending Library
10. Helpful Fact Sheets on a variety of dementia-related topics
11. Professional Education
12. Community Education

Outreach and Marketing

- Each Line does outreach and marketing activities statewide to promote its phone number and areas of expertise.
- Joint promotion of each separate Line will be done when possible.

Training/Best Practices

- To ensure the Lines are providing high-level service statewide, adhering to uniform referral protocols and standards, and are able to share best practices and expertise, trainings for Information Helpline and SLL will be provided.
    - The Alzheimer's Association will provide on-site training in dementia identification and referral to Senior Linkage Line® staff at each Senior Linkage Line® call center.
- Joint conference calls with Line staff may be held to ensure communication on an ongoing basis.

STEP BY STEP INSTRUCTIONS FOR REFERRAL CLIENT TRACKING FIELDS

Step 1: Senior/Beneficiary—New Call

1. **First Name:** Enter the first name of the beneficiary/senior. This will transfer to the Basic Data screen.

2. **Last Name:** Enter the last name of the beneficiary/senior. This will transfer to the Basic Data screen.

3. **Zip Code:** Enter the zip code of the beneficiary/senior. When you enter the zip code it will automatically calculate city and county. This will transfer to the Basic Data screen.

4. **Home Phone:** Enter the home telephone number (including area code) of the beneficiary/ senior. This will transfer to the Basic Data screen.

Step 1: Senior/Beneficiary—Basic Data

1. **First Name**: Enter the first name of the beneficiary/senior. This transfers from the New Caller screen.

2. **Last Name:** Enter the last name of the beneficiary/senior. This transfers from the New Caller screen. Do *NOT* enter "Mr./Mrs./Ms." in the event you do not have a first name. This affects searching for repeat callers.

3. **Middle Name:** Enter the middle name of the customer.

4. **Organization:** Enter the organization the senior/beneficiary is with (if applicable).

5. **Zip Code:** Enter the zip code of the beneficiary/senior. When you enter the zip code it will automatically calculate city and county. This transfers from the New Caller screen.

6. **City, State:** Enter the city, state of the beneficiary/senior. This is automatically calculated by entering the zip code.

7. **County, State:** Enter the city, state of the beneficiary/senior. This is automatically calculated by entering either the zip code or city, state.

8. **Address 1:** Enter the first line of the address of the beneficiary/senior.

9. **Address 2:** Enter the second line of the address of the beneficiary/senior (if applicable).

10. **Birth date:** Enter the birth date of the beneficiary/senior. You must use the format mm/dd/yyyy.

11. **Age:** Enter the age of the beneficiary/senior. This is automatically calculated by entering the birth date.

12. **Home Phone:** Enter the home telephone number (including area code) of the beneficiary/ senior. This transfers from the New Caller screen.

13. **Work Phone:** Enter the work telephone number (including area code) of the beneficiary/ senior.

14. **Fax:** Enter the fax number (including area code) of the beneficiary/senior.

15. **E-Mail:** Enter the e-mail address of the beneficiary/senior.

16. **Gender:** Select the appropriate gender of the beneficiary/senior.
    - Male
    - Female
    - Unknown

17. **Ethnicity:** Select the appropriate ethnicity of the beneficiary/senior.
    - African American/Black: A person having origins in any of the Black Racial groups of Africa. Terms such as “Haitian” or “Negro” can be used in addition to Black or African American.
    - American Indian/Alaska Native: A person having origins in any of the original peoples of North or South America including Central America and who maintains tribal affiliations or community attachments.

- Asian: A person having origins in any of the original people of the Far East, Southeast Asia, or Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- Hispanic/Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin, regardless of race. The term "Spanish Origin" can be used in addition to "Hispanic" or "Latino."
- Pacific Islander/Native Hawaiian: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- White, Not Hispanic: A person having origins in any of the original peoples of Europe, Middle East, or North Africa.
- Other: anything other than one of the classification listed above.
- Not collected: information not collected.

18. **Language Spoken:** Language spoken by customer if other than English. Do *NOT* enter English if the customer speaks English.

19. **Has Disability:**
    - No, if the senior/beneficiary does not have a disability.
    - Yes, if the senior/beneficiary self identifies as having a disability or through the course of the interview you determine he or she has an impairment that limits a major life activity.
    - Medicare Disabled, if the senior/beneficiary is a beneficiary of Medicare due to having a disability or end-stage renal disease.
    - Not collect, if the question was not asked (this field is default).

Step 1: Senior/Beneficiary—Assistance

1. **Income:** Enter the gross income that applies to the beneficiary/senior. These categories refer to the monthly "household" income of the consumer or the consumer and spouse only, not other relatives with whom the client might be living.

2. **Number in Household:** Enter the total number of people living in the household of the beneficiary/senior receiving services regardless of whether their income and/or assets are included in eligibility discussions. For persons being screened under 65 years of age, count any dependent children (under 18 years of age) as part of the number in household. Do not include children's income for eligibility purposes.

3. **Assets:** Enter the asset that applies to the beneficiary/senior. These categories refer to the total "household" assets of the consumer or the consumer and spouse only, not other relatives with whom the client might be living.

4. **Eligible for Medicare Savings:**
    - Yes, if a consumer is eligible for a Medicare Savings Program (MSP)
    - No, if a consumer is not eligible for an MSP

- Not applicable, do not select this choice

5. **Reason Not Eligible:** If customer called for information on a Medicare Savings Program, including the MN Prescription Drug Program, and customer is not eligible, select from the pick list which best describes why customer is not eligible.
   - Assets Too High
   - Income and Assets Too High
   - Income Savings *(choose this when receiving the Medicare Savings Program benefit, i.e., Part B premium, makes them ineligible for the program)*
   - Income Too High
   - Long-Term Care Facility
   - Not a Minnesota Resident
   - Not Applicable
   - Not Enrolled in Medicare *(choose this for people under 65 who are attempting to enroll in the prescription drug program, but do not have Medicare)*
   - Other
   - Other Drug Coverage

6. **Reason Not Apply:** If a customer is eligible for the Medicare Savings Program, but is not going to apply, select from the pick list which best describes why customer will not apply.
   - Estate Recovery
   - Family Discouraged
   - Not Applicable
   - Other
   - Paperwork
   - Stigma
   - Unknown

7. **FYI Dollars Saved:** Enter the amount of recoupment of private funds returned to a beneficiary from either an insurance agency or a medical provider. This includes any cases of Medicare or Medicaid fraud situations, or waste or abuse of Medicare or Medicaid dollars, for example, billing errors, appeals, etc. Any money claimed for recoupment must have documentation available to prove recoupment. Documentation includes a statement with the Provider name, name of beneficiary, and dollar amount saved. Documentation can be from the Senior LinkAge Line® system electronic client tracking system, as long as it includes these fields. Please send documentation to the CIAA team whenever you enter a number into the Assistance tab, F7, "FYI dollars saved." Do NOT include any actual Medicare dollars saved as these are to be reported to the Medicare contractors separately as explained in the beginning section of IM #07-02. Do NOT use dollar signs and the field will NOT accept non-numerical characters (letters).

8. **Application Sent:**
   - Yes, if an application was sent to the customer

- No, if an application was not sent
- Not applicable, do not select this choice

9. **Type of Application Sent:** Use this space to type in the type of application that was sent to the customer. Please type in "MN HealthCare Application" if you have sent an application for the MSP.

10. **Child Has a Disability:** If a grandparent or step-grandparent is raising a grandchild, select
    - Yes, if the child has a disability
    - No, if the child is not disabled
    - Not applicable, if a grandparent or step-grandparent is NOT raising a grandchild

11. **Type of Service:** Select the item from the drop-down box that best describes the type of contact with the customer.
    - *Hang-up:* Senior LinkAge Line® specialist leaves a voice mail message for a caller or a caller goes to voice mail but hangs up and does not leave a message.
    - *Information and referral*: Senior LinkAge Line® specialist does the below and/or provides a list of service providers and contact information of those service providers that may include things like fees, or eligibility requirements to the caller regarding services to consumers. May include providing education on the presenting problem.
    - *Information only*: Senior LinkAge Line® specialist answers a question or provides education for the caller regarding services to consumers.
    - *Information, referral, and assistance*: Senior LinkAge Line® specialist provides the above listed and/or connects the consumer to the provider directly (may involve a 3-way call, or the specialist calling the provider with the consumer's issues and contact information). The Senior LinkAge Line® specialist asks probing questions to determine the range of need of services for the consumer. The Senior LinkAge Line® specialist will strive to connect with the consumer at a later date/time to make sure the caller received what he needed. The Senior LinkAge Line® specialist provides education on the options available regarding the presenting problem and discusses with the consumer the best option for his situation.

12. **Customer Satisfaction Survey Sent:**
    - Yes, from the pick list if the information and assistance customer satisfaction survey has been sent to the customer
    - No, if no information and assistance customer satisfaction survey was sent to the customer
    - Not applicable, do not select this choice

13. **Medical Funds:** Use this space to type in money saved or recouped to Medicaid.

14. **Other Savings:** Use this space to type in any money saved or recouped to any entity other than Medicare, Medicaid, or beneficiaries (e.g., secondary health insurance).

Step 1: Senior/Beneficiary—RxConnect

1. **Enrolled in PDP:**
    - Yes, if the customer is enrolled in the MN Prescription Drug Program
    - No, if the customer is NOT enrolled in the MN Prescription Drug Program
    - Not applicable, do not select this choice

2. **# drugs not in Indicare:** Enter the total number of prescription drugs customer is requesting assistance with that are NOT in Indicare.

3. **Sent med mgt tips:**
    - Yes, if a medication management tip sheet was sent to the customer
    - No, if a medication management tip sheet was not sent to the customer
    - Not applicable, do not select this choice

4. **Sent RxConnect packet:**
    - Yes, if an RxConnect packet was sent to the customer
    - No, if an RxConnect packet was not sent to the customer
    - Not applicable, do not select this choice

5. **# of applications sent:** Enter the total number of non-Indicare patient assistance applications that were sent.

6. **Estimated cost savings:** Enter the estimated cost savings from non-Indicare patient assistance applications. If unsure leave BLANK.

7. **MN RxConnect #:** Enter how many of the MN RxConnect Pharmacy forms you assisted the client with.

8. **MN RxConnect Pharmacy:**
    - Canada Drug Pharmacy
    - Canada UK Pharmacy
    - Granville Pharmacy (Canada)
    - Granville Pharmacy (UK)
    - Not applicable
    - Total Care Pharmacy (Canada)
    - Total Care Pharmacy (UK)

Step 1: Representative Caregiver—New Caller

1. **First Name:** Enter the first name of the representative/caregiver. This will transfer to the Basic Data screen.

2. **Last Name:** Enter the last name of the representative/caregiver. This will transfer to the Basic Data screen.

3. **Organization:** Enter the organization of the representative/caregiver. This will transfer to the Basic Data screen.

4. **Zip Code:** Enter the zip code of the representative/caregiver. When you enter the zip code it will automatically calculate city and county. This will transfer to the Basic Data screen.

5. **Home Phone:** Enter the home telephone number (including area code) of the representative/caregiver. This will transfer to the Basic Data screen.

6. **Work Telephone:** Enter the work telephone number (including area code) of the representative/caregiver. This will transfer to the Basic Data screen.

Step 1: Representative Caregiver—Basic Data

1. **First Name**: Enter the first name of the representative/caregiver. This transfers from the New Caller screen.

2. **Last Name:** Enter the last name of the representative/caregiver. This transfers from the New Caller screen. Do *NOT* enter "Mr./Mrs./Ms." in the event you do not have a first name. This affects searching for repeat callers.

3. **Middle Name:** Enter the middle name of the representative/caregiver.

4. **Organization:** Enter the organization the representative/caregiver is with (if applicable).

5. **Address 1:** Enter the first line of the address of the representative/caregiver.

6. **Address 2:** Enter the second line of the address of the representative/caregiver (if applicable).

7. **Zip Code:** Enter the zip code of the representative/caregiver. When you enter the zip code it will automatically calculate city and county. This transfers from the New Caller screen.

8. **City, State:** Enter the city, state of the representative/caregiver. This is automatically calculated by entering the zip code.

9. **County, State:** Enter the city, state of the representative/caregiver. This is automatically calculated by entering either the zip code or city, state.

10. **Home Phone:** Enter the home telephone number (including area code) of the representative/caregiver. This transfers from the New Caller screen.

11. **Work Phone:** Enter the work telephone number (including area code) of the representative/ caregiver.

12. **Extension:** Enter the extension of the work telephone number of the representative/caregiver (if applicable).

13. **Fax:** Enter the fax number (including area code) of the representative/caregiver.

14. **E-Mail:** Enter the e-mail address of the representative/caregiver.

15. **Language Spoken:** Language spoken by representative/caregiver if other than English. Do *NOT* enter English if the representative/caregiver speaks English.

16. **Birth date:** Enter the birth date of the representative/caregiver. You must use the format mm/dd/yyyy.

17. **Age:** Enter the age of the representative/caregiver. This is automatically calculated by entering the birth date.

18. **Gender:** Select the appropriate gender of the representative/caregiver.

19. **Ethnicity:** Select the appropriate ethnicity of the representative/caregiver.
    - African American/Black: A person having origins in any of the Black Racial groups of Africa. Terms such as “Haitian” or “Negro” can be used in addition to Black or African American.
    - American Indian/Alaska Native: A person having origins in any of the original peoples of North or South America including Central America and who maintains tribal affiliations or community attachments.
    - Asian: A person having origins in any of the original people of the Far East, Southeast Asia, or Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
    - Hispanic/Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin, regardless of race. The term “Spanish Origin” can be used in addition to “Hispanic” or “Latino.”
    - Pacific Islander/Native Hawaiian: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
    - White, Not Hispanic: A person having origins in any of the original peoples of Europe, Middle East, or North Africa.
    - Other: anything other than one of the classification listed above.
    - Not collected: information not collected.

Step 1: Representative/Caregiver—Caregiver Relationship

1. **Caregiver Relationship:**
   - Adult Child
   - Friend/Neighbor
   - Not applicable
   - Relative
   - Representative
   - Spouse/Partner

2. **Lives With Care Receiver:**
   - Yes, if the caregiver lives with the care receiver
   - No, if the caregiver does not live the care receiver
   - Not applicable, do not select this choice

3. **Age 60+ Caregiver of Child 18:** Are you raising your grandchild?
   - Yes, Grandparent or step-grandparent of a child by blood or marriage, who is 60 years of age or older and:
     - lives with the child;
     - is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and
     - has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally
   - No, if the above criteria are not met
   - Not applicable, if there is no child in the household

4. **Care Receiver:** Does the person receiving care have memory loss—Yes or No. If caller sounds unsure ask probing questions (10 warning signs):
   - Does he or she forget things more often?
   - Forget how to use the stove or make lunch?
   - Forget the names of simple things like toothbrush and instead will say "that thing for my mouth"?
   - Forget where they are or how they got there?
   - Wear inappropriate clothing—an overcoat in July, shorts/sandals in February, nightgown to get groceries?
   - Forget what adding and subtracting is?
   - Rapid changes in mood, cry one moment, laugh the next?
   - Extremely suspicious, fearful or dependent on a family member?
   - Has become very passive, sits in front of the TV for hours, sleeps all the time, isn't interested in things they used to love to do—knitting, woodworking, etc.

   If yes—pop up or new field? And automatic connection to Memory Loss problem need field for referrals
   - Have you talked to anyone about this? (Refer to Alzheimer's Association or Caregiver Coach)

- Are you receiving any services? (Refer to SOS worker and/or Alzheimer's Association)
- Are you feeling overwhelmed? (Refer to Alzheimer's Association or Caregiver Coach)

Step 1: Part D/LIS

1. **LIS Eligibility:** If the Social Security Administration has determined the client to be eligible for Extra Help (Low Income Subsidy) select "yes" from the pick list. Default is "Not Applicable."

2. **How LIS Applied For:** Select the item from the pick list that best describes how the client applied for the Extra Help. Default is "Not Applicable."
   - Internet
   - Mailing
   - Phone

3. **LIS App Completed:** Select the item from the pick list that best describes the assistance provided by Linkage Line staff or contractor with applying for the LIS. Default is "Not Applicable."
   - Already completed
   - Application mailed
   - Deemed
   - Not Applicable
   - Refused
   - Yes

4. **Reason Refused LIS:** If the client refuses LIS assistance, select the item from the pick list that best describes the reason for refusal. Default is "Not Applicable."
   - Creditable drug coverage
   - Family discouraged
   - Non-creditable drug coverage
   - Not Applicable
   - Other benefits reduced
   - Paperwork
   - Stigma
   - Too confusing

5. **Heard About LIS**: Select the item from the pick list that best describes how the client heard about LIS. Default is "Not Applicable."
   - 211
   - Brochure
   - Called before
   - Church/Parish nurse

- CMS Mailing
- County Social Services
- DHS Mailing
- Dining Site
- Drug Company
- Flyer/Poster
- Insurance Agents
- Kiosk/ADRC
- Library
- MBA
- Medicare
- Minnesotahelp.info
- Newsletter
- Newspaper
- Not Applicable
- Other
- Other Agency
- Other Web Site
- Pharmacy
- Physician/Clinic
- Presentation
- Radio
- Senior LinkAge Line
- Social Security
- SSA Mailing
- Television
- Word of Mouth

6. **Help Select Part D Plan:** Did Linkage Line staff assist the client with selecting a Medicare Part D plan? Select the option that best completes this question. Default is "Not Applicable."

7. **How Enrolled in Plan:** Select the item from the pick list that best describes how the client enrolled in a Part D plan. Default is "Not Applicable."
    - Medicare Auto-enrolled
    - Medicare Passive enrolled
    - Not Applicable
    - Online Plan application
    - Written Plan application

8. **Reason no plan:** If the client did not enroll in a plan, select the item from the pick list that best describes why the client did not enroll. Default is "Not Applicable."
    - Creditable Drug Coverage
    - Family Discouraged

- Incomplete Formulary
- Non-creditable Drug Coverage
- Not Applicable
- Other Benefits Reduced
- Paperwork
- Stigma
- Too Confusing

9. **Type Plan Selected**: Select the plan category from the pick list that best describes the plan client selected to receive their drug coverage. Default is "Not Applicable."
    - Cost Plan
    - MA-HMO Plan
    - MA-MSA Plan
    - MA-PFFS Plan
    - MA-PPO/MA-PD Plan
    - MA-SNP
    - Not Applicable
    - Stand Alone Plan

Step 1: SPAP Transition (From Minnesota Prescription Drug Program to Part D)

1. **Caller SPAP Enrollee:** Is the caller enrolled in the SPAP? Select the option that best answers this question. Default is "No."

2. **SPAP Assistance Refused:** If the SPAP enrollees refuses assistance from the Linkage Line staff, select the option from the pick list that best describes the reason for the refusal.
    - Formulary Issues
    - Not Applicable
    - Spend down Issues
    - Too Confusing

3. **SPAP Appeal**: Is the SPAP enrollee planning to appeal the end of the SPAP in MN? Select the option that best answers this question.

4. **SPAP Contacted By:** Select the option from the pick list that indicates who contacted the SPAP enrollee for assistance.

5. **First SPAP Contact Outcome**: Select the option from the pick list that best describes the outcome of the first contact Linkage Line staff had with the SPAP enrollee.

    - Compare/Evaluate Plans and Enroll
    - Declined 1:1 Assistance
    - Declined Resources Offered
    - Need 1:1 Compare/Eval Plans

- Need 1:1 Enrolled in Plan
- Need 1:1 SPAP Appeal
- No Answer and Letter Sent
- Not Applicable
- Terminated Call
- Voice Message Left

6. **Second SPAP Contact Outcome:** Select the option from the pick list that best describes the outcome of the second contact Linkage Line staff has with the SPAP enrollee.

    - Compare/Evaluate Plans and Enroll
    - Declined 1:1 Assistance
    - Declined Resources Offered
    - Need 1:1 Compare/Eval Plans
    - Need 1:1 Enrolled in Plan
    - Need 1:1 SPAP Appeal
    - No Answer and Letter Sent
    - Not Applicable
    - Terminated Call
    - Unable to Reach for 1:1
    - Voice Message Left

7. **Third SPAP Contact Outcome:** Select the option from the pick list that best describes the outcome of the third contact Linkage Line staff has with the SPAP enrollee.

    - Compare/Evaluate Plans and Enroll
    - Declined 1:1 Assistance
    - Declined Resources Offered
    - Need 1:1 Compare/Eval Plans
    - Need 1:1 Enrolled in Plan
    - Need 1:1 SPAP Appeal
    - No Answer and Letter Sent
    - Not Applicable
    - Terminated Call
    - Unable to Reach for 1:1
    - Voice Message Left

8. **Fourth SPAP Contact Outcome:** Select the option from the pick list that best describes the outcome of the fourth contact Linkage Line staff has with the SPAP enrollee.

    - Compare/Evaluate Plans and Enroll
    - Declined 1:1 Assistance
    - Declined Resources Offered
    - Need 1:1 Compare/Eval Plans

- Need 1:1 Enrolled in Plan
- Need 1:1 SPAP Appeal
- No Answer and Letter Sent
- Not Applicable
- Terminated Call
- Unable to Reach for 1:1
- Voice Message Left

9. **Fifth SPAP Contact Outcome:** Select the option from the pick list that best describes the outcome of the fifth contact Linkage Line staff has with the SPAP enrollee.

    - Compare/Evaluate Plans and Enroll
    - Declined 1:1 Assistance
    - Declined Resources Offered
    - Need 1:1 Compare/Eval Plans
    - Need 1:1 Enrolled in Plan
    - Need 1:1 SPAP Appeal
    - No Answer and Letter Sent
    - Not Applicable
    - Terminated Call
    - Unable to Reach for 1:1
    - Voice Message Left

Review: Call Review

1. **Contacted SLL By:** Select the item from the pick list that best describes how the consumer "contacted us" to receive services.
    - Agency Line
    - E-mail
    - Fax
    - Mail
    - Other
    - Senior LinkAge Line
    - Walk-In
    - Web Site

2. **Call or Contact Made By:** Select from the pick list which best describes who made the call or contact.
    - Agency: A professional from a service, program, or provider who is requesting information and assistance for a client or consumer.
    - Beneficiary/Self: A consumer who is requesting information and assistance for him- or herself.
    - Caregiver (family member, conservator): A person, not from an agency, who is requesting information and assistance for another person.

- Couple: A person who is requesting information and assistance for him- or herself and spouse.

3. **Number of Contacts Out:** Enter the total number of each time the Senior LinkAge Line® specialist makes a contact on behalf of a consumer.
    - Calling an agency or provider on behalf of a consumer or other collateral calls.
    - Mailing, faxing, e-mailing (or other communication mediums) information to a consumer.
    - Follow-up a contact with a consumer to ensure a connection was made.

4. **Heard About SLL (1):** Select the item from the pick list that best describes how the consumer initially heard about the Senior LinkAge Line®. This field is only completed for the initial contact. This field is mandatory with every consumer file.
    - 211
    - AARP
    - Brochure
    - Called Before
    - CDCS Postcards
    - CDT
    - Church
    - DHS Mailing
    - Did Not Ask
    - Dining Site
    - Drug Company
    - Flyer/Poster
    - Kiosk
    - Library
    - Mailing
    - Medicare
    - Minnesota Board on Aging
    - MNHelp.info
    - MN RxConnect
    - Newsletter
    - Other
    - Other Agency
    - Other Web Site
    - Pharmacy
    - Phone Book
    - Physician/Clinic
    - Presentation
    - Promotional Item (Magnet)
    - Radio
    - SLL Outbound
    - Social Security

- Television
- Word of Mouth

5. **Referral Mode:** Select the most appropriate setting in which I&A services were provided to the consumer.
    - Center
    - Church
    - Clinic
    - E-mail
    - Fax
    - Home Visit
    - Library
    - Non-governmental Setting
    - SLL
    - Telephone
    - Walk-In

6. **Call Handled By:** Select the specialist or volunteer who worked with the caller.

APPENDIX 3
ADRC MARKETING CAMPAIGN KIOSK CARD

Age Well Live Well
Plan Well Care Well

Concerns about memory loss?

It's not uncommon to occasionally forget dates or lose items, and these events may become more common with age. If memory problems interfere with day-to-day activities, get information, care, and support as early as possible.

If you or someone you know has one or more of the following warning signs, ask a doctor for a complete exam for Alzheimer's Disease or related memory loss conditions:

- **Memory loss**: forgetting such things as appointments, names or telephone numbers often and not remembering them later
- **Trouble doing everyday tasks:** such as preparing a meal, using a household appliance or participating in a familiar hobby
- **Problems with language:** often forgetting simple words or using unusual words
- **Confused about the time and place:** such as getting lost on one's own street

- **Poor or decreased judgment:** such as using poor judgment and giving away large sums of money or paying for home repairs that aren't needed
- **Problems with abstract thinking:** such as forgetting how to balance a checkbook
- **Losing things:** or putting them in unusual places such as putting an iron in the freezer
- **Changes in mood or behavior:** such as rapid mood swings-from calm-to tears-to anger for no clear reason
- **Changes in personality:** becoming confused, suspicious, fearful, or overly dependent on a family member
- **Loss of energy and "get up and go."** Sitting in front of the television for hours, sleeping more than usual and not wanting to do usual activities

For information, call the Alzheimer's Association Information Helpline at 1-800-232-0851 or visit www.alzmndak.org.

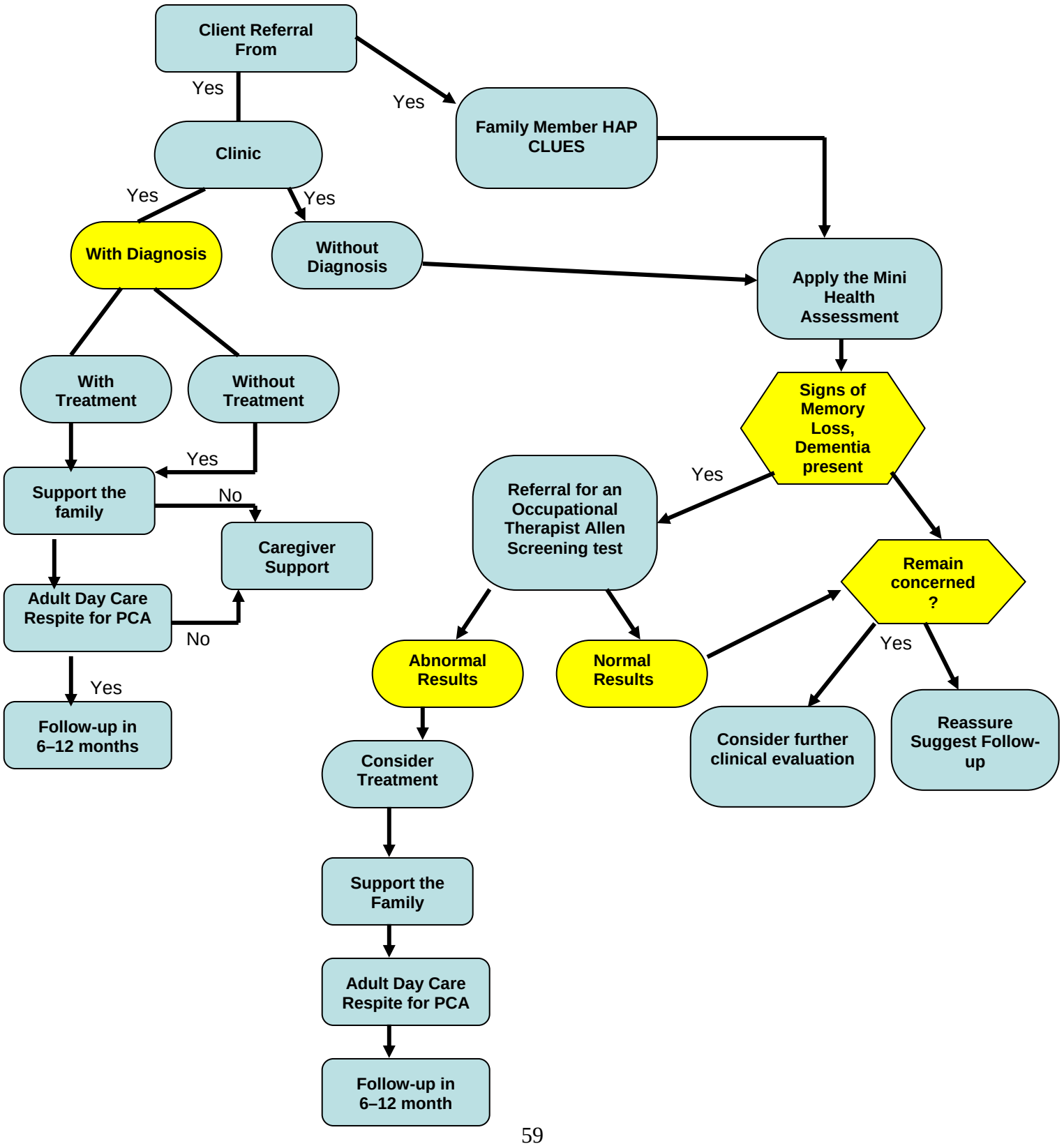
To learn about services for people with Alzheimer's Disease or related memory loss conditions, call the Senior LinkAge Line™ at 1-800-333-2433 or visit www.MinnesotaHelp.info.

Source: Adapted from the Alzheimer's Association, 2003. *10 Warning Signs of Alzheimer's Disease.*

This information is available in other forms to people with disabilities by contacting us at 651-431-2500 or 1-800-882-6262 or through the Minnesota Relay Services at 711 or 1-800-627-3529 (TDD), 1-877-627-3848 (speech-to-speech relay services).

Funding for this project is provided by a grant from the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services through the Minnesota Board of Aging.

APPENDIX 4
FLOW CHART FOR IDENTIFICATION AND MANAGING DEMENTIA
USED BY BRIDGE PARTNERSHIP MEMORY LOSS PROJECT



APPENDIX 5
COMMUNITY CARE PLAN AND SIX LEVELS OF FUNCTIONING

Memory Disorders Clinic
1245 15th Street N.
St. Cloud, MN 56303
320.203.2087

Community Care Plan

Initial Plan Date:_____ Updates: 1)_____ 2)_____ 3)_____ 4)_____ 5)_____ 6)_____ 7)_____ 8)_____ 9)_____

Client Name:_____ DOB:_____ Primary Care Physician:_____

Client Address:_____ Phone:_____ Clinic:_____ Phone:_____

_____ Address:_____

Caregiver Name:_____ DOB:_____ Community Support Agencies:

Caregiver Address:_____ Phone:_____ _____

_____ _____

_____

MDC Case Manager: April Stadtler, LGSW Phone: 320.203.2092 _____

Advanced Directives: ☐ Yes ☐ No Financial Responsibility & Assistance:

☐Living Will ☐Health Care Proxy:_____ _____

☐Health Care Directive ☐Conservator:_____ _____

☐Guardian:_____ _____

Emergency or Back-up Plan for Caregiver:

1.)
2.)
3.)

Education/Information Provided:

☐Getting a Diagnosis	☐Family Coping	☐Advanced Planning	☐Homecare	☐Alternative Living
☐AD & Disease Progression	☐Medications	☐Mood & Personality Changes	☐LTCC	☐PCP Partnership
☐Caregiver Stress	☐Respite	☐Physical Changes	☐Communication	☐End of Life Care
☐Caregiver Skills Training	☐Support Groups	☐Behavior Interventions	☐Grief	☐Other:

Alzheimer's Association 24/7 Helpline: 1.800.232.0851
www.alzmndak.org

Client Name:_____
DOB:_____

	Client CPT Score: Client MMSE Score:	Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	Goals	
							Client	Caregiver
Phase I: Initial Identification Phase	**CPT: 6.0 - 5.6** *Independent* Monitor for Changes	☐	☐ ☐	☐				
	CPT: 5.5 - 5.0 *Impairment in Executive Functioning* *Requires Monitoring of IADLs* *Completes tasks through trial & error* **Strengths:** Independent with Basic ADLs Able to complete tasks Other: Other: **Disabilities: IADLs** Driving Employment Money Management Shopping Medication Management Long Term or Event Planning Nutrition Other: Other: **Mood or Personality Changes:** ☐ Sleep Changes ☐ Depression ☐Changes in Appetite ☐ Impulsivity ☐Disinhibition ☐Other: ☐ Other:	

Client Name:_____
DOB:_____

Client CPT Score:
Client MMSE Score:

		Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	Goals	
							Client	Caregiver
Phase II: Longitudinal Monitoring and Treatment	**CPT: 4.9-4.5** *Dependence in Instrumental ADLs* *Completes tasks through trial & error* *Unable to generalize* *At risk living alone* **Strengths:** Goal Directed Completes tasks with cues and reminders Routine Oriented Concrete Thinking **Disabilities: IADLs** Driving Employment Money Management Shopping Housekeeping Medication Management Long Term or Event Planning Nutrition Other: Other: **Mood or Personality Changes:** **Mood or Personality Changes:** ☐ Sleep Changes ☐ Depression ☐Changes in Appetite ☐ Impulsivity ☐Disinhibition ☐Other: ☐ Other:		☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐				

Signatures:

Client/Caregiver follow-up:
1.)_____
2.)_____

MDC follow-up:
1.)_____
2.)_____

Client Name:_____
DOB:_____

	Client CPT Score: **Client MMSE Score:**	Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	**Goals**	
							Client	Caregiver
Phase II: Longitudinal Monitoring and Treatment	**CPT: 4.4-4.0** *Impairment in Basic ADLs* *Unable to find their way* *Learning is Difficult* *Unable to use rationale or reason* *Unsafe Living Alone*							
	Strengths: Goal Directed Completes tasks with cues and reminders Routine Oriented Concrete Thinking							
	Disabilities:	☐	☐	☐				
	Dependence with IADLs	☐	☐	☐				
	ADLs							
	Dressing	☐	☐	☐				
	Grooming	☐	☐	☐				
	Bathing	☐	☐	☐				
	Toileting	☐	☐	☐				
	Eating	☐	☐	☐				
	Other:	☐	☐	☐				
	Other:	☐	☐	☐				
	Mood or Personality Changes: ☐ Sleep Changes ☐ Depression ☐Changes in Appetite ☐ Impulsivity ☐Disinhibition ☐Other:							

Client/Caregiver follow-up:
1.)_____
2.)_____

MDC follow-up:
1.)_____
2.)_____

Client Name:_____
DOB:_____

Client CPT Score:

Client MMSE Score:

		Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	Goals	
							Client	Caregiver
Phase II: Longitudinal Monitoring and Treatment	**CPT: 3.9-3.5** *Impairment in Basic ADLs* *Wanders* *Unable to Reason or Learn New Information* *No Longer Goal Directed* **Strengths:** Can Complete Tasks with Demonstration and Tactile Cueing Routine Oriented Concrete Thinking Enjoys Socializing/Aware of Others Impaired Communication **Disabilities:** Dependence with IADLs ADLs Dressing Grooming Bathing Toileting Eating Difficulty with Motor Coordination Incontinence Visual Spatial Difficulties Other: **Mood or Personality Changes:** ☐ Sleep Changes ☐ Depression ☐Changes in Appetite ☐ Impulsivity ☐Disinhibition ☐Other:		☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐				

Signatures:

Caregiver follow-up:
1.)_____
2.)_____

MDC follow-up:
1.)_____
2.)_____

Client Name:_____
DOB:_____

	Client CPT Score: Client MMSE Score:	Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	Goals	
							Client	Caregiver
Phase II: Longitudinal Monitoring and Treatment	**CPT: 3.4-3.0** *Dependence in Basic ADLs* *Wanders* *Unable to Reason or Learn New Information* *Non-Goal Directed* *Impaired Communication* *May Not be Able to ID Objects* **Strengths:** Can Complete Tasks with Demonstration and Tactile Cueing Routine Oriented Reacts to Environment Stimuli Enjoys Socializing/Aware of Others **Disabilities:** Dependence with IADLs Dependence with ADLs Impaired Motor Coordination Incontinence Visual Spatial Difficulties Wandering Other: Other: **Mood or Personality Changes:** ☐ Sleep Changes ☐ Depression ☐Changes in Appetite ☐ Impulsivity ☐ Agitation ☐Disinhibition ☐Other:							
		☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐				

Signatures:

Caregiver follow-up:
1.)_____
2.)_____

MDC follow-up:
1.)_____
2.)_____

Client Name:_____
DOB:_____

	Client CPT Score: Client MMSE Score:	Caregiver Manages	Client Manages	Family Manages	Community Agency	Agency Contact	Goals	
							Client	Caregiver
Phase II: Longitudinal Monitoring and Treatment	**CPT: 2.9-2.0** *Dependence in ADLs* *Unable to Reason or Learn New Information* *Impaired Communication* *Impaired Protective Reflexes* *May Not be Able to ID Objects or People* **Strengths:** Able to Move (sit, stand) and Walk About Routine Oriented Reacts to Internal Stimuli Automatic Actions Intact such as Ability to Chew and Swallow Finger Food **Disabilities:** Dependence with IADLs Dependence with ADLs Impaired Motor Coordination Incontinence Tunnel Vision Wandering Falls Eating Difficulties (i.e. pockets food) Other: Other: **Mood or Personality Changes:** ☐Sleep Changes ☐Agitation ☐Resistive to Care ☐Other:							
		☐	☐	☐				
		☐	☐	☐				
		☐	☐	☐				
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		☐	☐	☐				
		☐	☐	☐				

Signatures:

Caregiver follow-up:
1.)_____
2.)_____

MDC follow-up:
1.)_____
2.)_____

6 Levels of functioning

Allen Level	Information Processed	Activity Capacity	Caregiver Assistance
Level 6 Planned Actions	Abstract or complex cues, hypothetical ideas, symbols, numbers, written information Situations	Complicated ADLs Plans Ahead, anticipates results Situational awareness, effects on others	None
Level 5 Exploratory Action & Independent Learning	Complex with Errors, end product/outcome Situations	Low level complexity, segments of complicated activity, self-care routines Situational Awareness, effect on others	Simplify/do together complex activities, monitor hazards, solve problems
Level 4 Goal Directed	Concrete visual cues, end product/outcome Situations	Concrete activities, few steps, visual outcomes, self-care routines with set-up and reminders Basic awareness, effects on self	Eliminate or simplify complex activity, restrict hazards, solve problems Expect misunderstandings, avoid reasoning, reassure
Level 3 Manual Actions	Manual actions associated with objects Situations	Use of objects, parts of self-care Vague awareness or unaware	Step-by-step, set-up, help to start, sequence, end Refocus task, keep directions simple, avoid reasoning, reassure
Level 2 Postural Reactions	Gross body movements, touch	Moving to assist or resist cares May self feed	Total care, prevent falls, provide stimuli & comfort in environment
Level 1 Automatic Reactions	Internal	Reflexive Actions	Total care, attend to comfort

Developed by Claudia Kay Allen, MA, OTR, FAOTA