

# FAMILY CAREGIVERS AND THE NEW MEXICO AGING NETWORK

REPORT 2009



*Partners in Lifelong Independence and Healthy Aging*

# FAMILY CAREGIVERS AND THE NEW MEXICO AGING NETWORK

## 2009 Report

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### **Executive Summary**

The New Mexico Aging and Long-Term Services Department (ALTSD) receives both federal and state funds to provide a variety of family caregiver support services. In addition to that funding, the Department was awarded a federal grant through the US Administration on Aging Alzheimer's Disease Supportive Services Program in July 2007, to improve the capacity of New Mexico's home and community-based long-term care service delivery system to address the needs and issues of people with Alzheimer's disease and other dementias and their caregivers. This report has been developed as one of the products of the grant. The intent of the report is to provide a foundation for future strategic planning and needs assessment, as well as a tool for information and education about the needs and issues of family caregivers in New Mexico.

### **Who are Family Caregivers?**

Most people—wives, daughters, husbands, sons, grandchildren, relatives, friends and neighbors—at some point in their lives become caregivers. The 2006 Older Americans Act defines family caregiver as an adult family member, or another individual, who is an informal provider of in-home and community care.

### **Numbers of Caregivers**

AARP reports that 44 million American caregivers provide unpaid care to adults in an estimated 22.9 million households. The Family Caregiver Alliance estimates there are 200,000 family caregivers in New Mexico.

### **Caregivers, Alzheimer's Disease and Other Dementias**

The Alzheimer's Association estimates that 40,000 New Mexicans age 65 or older will have Alzheimer's disease by the year 2010. Caring for a person with Alzheimer's disease is often very difficult, and many family caregivers experience high levels of emotional stress and depression as a result.

### **Costs of Caregiving**

The many measurable costs of caregiving include those that affect the workplace, the individual caregiver, and the related health and social-services providers.

### **The Need for Support**

Unpaid, family caregivers are the backbone of the US long-term care system. Support for family caregivers has been shown to help caregivers remain healthy, improve their caregiving skills, and remain in their caregiving roles longer. Evidence also shows that caregiver support can delay or prevent nursing home placement for the care recipient.

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### **Services and Supports – Putting the Pieces Together**

The New Mexico Aging Network provides an array of services and supports to family caregivers, such as information, assistance, resources, and supportive services. Aging Network caregiver providers include area agencies on aging, senior companion programs, the New Mexico Alzheimer's Association, projects funded under the federal Alzheimer's disease Supportive Services Program, the ALTSD Aging and Disability Resource Center, and home- and community-based waiver programs. In addition, an array of other community and national services is available for caregivers.

### **Service Delivery Considerations**

Studies have shown an underutilization of services by caregivers. Caregivers typically do not know where to turn to for information and assistance. Underutilization is particularly prevalent among minority and rural caregivers. It is particularly important that culturally and linguistically competent services and supports be available in New Mexico.

### **Implications**

The number of elders and adults with disabilities is beginning to outnumber the pool of potential caregivers. Caregivers are facing increased demands that affect their health and financial situations. Family caregivers need services and supports to remain healthy and to continue their caregiving roles. The number of people diagnosed with Alzheimer's disease and other dementias also continues to grow. Nearly all people with Alzheimer's disease eventually need more assistance than families and friends can provide and must move to long-term care settings.

### **Recommendations**

The 2009-2013 New Mexico State Plan for Aging and Long-Term Services contains objectives and activities surrounding Aging Network services and supports for caregivers and for persons with Alzheimer's disease and dementia. The Department's Policy Advisory Committee Alzheimer's Disease/Caregiver Workgroup supports the implementation of the objectives and activities contained in the plan. Further recommendations include:

#### ***Planning***

- Add the Caregiver Module to the New Mexico Behavioral Risk Factor Surveillance System (BRFSS).
- Develop an annual Caregiving Report to include updated statewide caregiving data, emerging needs and progress on objectives.
- Expand the mission of the ALTSD Policy Advisory Committee Alzheimer's Disease/Caregiver Workgroup to include facilitation of the development of state-wide planning for dementia.

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### ***Advocacy***

- Include caregivers on policy-making and decision-making boards – in government, the health care industry, and at the workplace.
- Explore the possibility of reintroducing state legislation regarding tax credits for caregivers.
- Support innovative strategies to finance long-term care, such as those identified at the 2001 Caregiver Empowerment Summit, including:
  - a mix of subsidized insurance, private insurance, tax credits and deductions;
  - stipends for family caregivers who choose to provide care themselves;
  - Social Security credits to those who leave the workplace to provide full-time caregiving;
  - development of caregiver ombudsmen, caregiver registries, caregiver joint purchasing arrangements, and care management services;
  - implementation of a pool of trained paid caregivers large enough to meet the growing need.

### ***Implementation***

- Include topic specific links for caregiver resources and assistance on aging network websites.
- Support the development of community caregiver coalition projects around the state. (A model for this could be Georgia's CARE-NET, a collaborative network of representatives from a variety of constituencies, including family care providers, area agencies on aging, educational institutions, businesses, and other interested groups.)
- Ensure that all service components are culturally and linguistically appropriate and meet the unique needs of rural populations.
- Establish family caregiving coaches and a 24-hour hotline for caregivers.
- Partner with community colleges to develop caregiver components for direct service paraprofessional curricula, such as certified nursing assistant training.
- Support expansion of supplemental services options, as funding allows, in each Aging Network Planning and Service Area.

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### **History**

The New Mexico Aging and Long-Term Services Department (ALTSD) receives federal funds, under the Older Americans Act (as amended 2000), Title III-E, and state funds to provide Family Caregiver Support Services throughout New Mexico. These services have been established to assist individuals engaged in the daily tasks of caring for older family members, as well as to support older adult caregivers of children and younger adult relatives with disabilities. The Department also receives state funds (Chapter 365 of the 1993 Laws of New Mexico and subsequent Appropriations Acts) and federal funds to provide services to persons with Alzheimer's disease and other dementias and their caregivers. Additionally, the Department was awarded a federal grant, under the US Administration on Aging Alzheimer's Disease Supportive Services Program, in July 2007 to "improve the capacity of New Mexico's home and community-based long-term care service delivery system to address the needs and issues of people with Alzheimer's disease and other dementias and their caregivers."

### **Purpose of the Report**

This report has been developed as one of the products of the 2007 federal Alzheimer's Disease Supportive Services Program grant from the US Administration on Aging. The intent of the report is to provide a foundation for future strategic planning and needs assessment. It is also designed as a tool for information and education regarding the needs and issues of family caregivers in New Mexico.

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### Who are Family Caregivers?

Most people, at some point in their lives, become caregivers. Caregivers are daughters, wives, husbands, sons, grandchildren, nieces, nephews, partners and friends. While some people receive care from paid caregivers, most rely on unpaid assistance from families, friends and neighbors.

Caregivers manage a wide range of responsibilities, they may:

- Buy groceries, cook, clean house or do laundry
- Help a family member get dressed, take a shower and take medicine
- Help with transferring someone in and out of bed, help with physical therapy, injections, feeding tubes or other medical procedures
- Make medical appointments and drive to the doctor and drugstore
- Talk with the doctors, care managers and others to understand what needs to be done
- Spend time at work handling crises or make plans to help family members who are sick
- Serve as designated "on-call" family members for problems

*Rosalyn Carter said it best:  
"There are only four kinds  
of people in the world –  
those who have been  
caregivers, those who are  
currently caregivers, those  
who will be caregivers and  
those who will need  
caregivers."*

The 2006 Older American's Act defines "family caregiver" as an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual, or to an individual with Alzheimer's disease or a related disorder, or to a child, or to an individual with a disability.

### National Data

The actual numbers of caregivers in the United States varies depending on the study being examined. Each research study utilizes different data-gathering methods, thus resulting in some disparity in data. Numbers of caregivers vary between 22.4 million to 54 million. According to the National Alliance for Caregiving and AARP (April 2004), "44.4 million American caregivers . . . provide unpaid care to other adults . . . in an estimated 22.9 million households."

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### New Mexico Data (From the Family Caregiver Alliance)

Total Population (millions)	1.9
Population 60+ (thousands)	315.5
Population 65+ (thousands)	229.5
Population 85+ (thousands)	26.8
% Population 65+ Below Poverty	11.9
% Population in Rural Areas	35.4
% Persons 65+ Living Alone	27.5
# of Caregivers	200,000
# of Caregiving Hours (millions)	220
% Grandparents Raising Grandchildren (thousands)	2.2

### Characteristics of Caregivers

The typical caregiver:

- Is female
- Is 35-64 years old (the average age is 63)
- Is married or living with a partner
- Is a member of an ethnic minority
- Is working outside the home while providing care (almost six in ten or 59%)
- Has had to make adjustments to work life (62%), “from reporting late to work to giving up work entirely” (National Alliance)

### Who Are the Care Recipients?

- Persons 21-64 years old, living with a disability, represented 14.9 thousand care recipients in New Mexico (reported in November 2007)
- Of those 65+ living with a disability, 44,500 reported receiving caregiving services

***Care recipients may be in need of assistance due to:***

- Physical impairments
- Alzheimer’s disease
- Other dementias and brain-impairing disorders (Family Caregiver Alliance)

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### Caregivers and Alzheimer's Disease and other Dementias

The Alzheimer's Association estimates that 40,000 New Mexicans age 65 or older will have Alzheimer's disease by the year 2010. Caring for a person with Alzheimer's disease is often very difficult, and many family caregivers experience high levels of emotional stress and depression as a result. People with Alzheimer's disease and other dementias are high users of health care, residential care and home and community based services" (ALTSD/PAC Issue Paper, Alzheimer's Disease).

- In New Mexico, it is estimated there are 58,446 family and other volunteer caregivers providing unpaid care for persons with Alzheimer's disease or other dementias.
- These caregivers provide over 50,450,900 hours of unpaid care per year.
- Many people with Alzheimer's disease or other dementias also have other serious medical conditions such as diabetes and congestive heart failure.\*
- Caregivers often have to manage other medical conditions in addition to dementia.\*

**The incidence of Alzheimer's disease for people over the age of 65 is one in eight; for those over the age of 85, it is nearly 50%.**

- Alzheimer's disease and other dementias cause memory loss, challenging behaviors and severe functional limitations.\*

- Caregivers of people with Alzheimer's disease and other dementias provide more hours of help, on average, than caregivers of other older people.\*

- The average number of hours of unpaid care provided for people with Alzheimer's disease and other dementias increases as the disease worsens.

**"Nearly one out of every four U.S. households (22million) provides care to a relative or friend aged 50 or older." (Women's Institute for a Secure Retirement.)**

\* From 2009 Alzheimer's Disease Facts and Figures

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### Costs of Caregiving

A caregiving cost study conducted by MetLife Mature Market Institute in July 2006 found that:

- Between 12-33 work days per year were missed by caregivers.
- One hour per week for 50 weeks, on average, was lost due to partial absenteeism, related to such activities as making arrangements for services, moving a loved one to a different living situation, or dealing with a hospitalization.
- The total estimated cost to employers for all full-time, employed caregivers is \$33.6 billion.
- Caregiving can entail more than 20 hours per week of unpaid care.
- The duration of caregiving can last from less than a year to more than 40 years, but on average lasts about 4.3 years.

***“Family caregivers are providing the majority of long-term care in this country. Many of these caregivers perform their work without coming into contact with social or health services despite their high levels of burden and depression.” (Butler, Turner, Kaye, Ruffin & Downey, 2005.)***

- Older caregivers, those age 50+, have been caregiving for more than 10 years.
- Caregiving is typically provided to an adult family member or a friend.
- According to the Family Caregiver Alliance, 83% of caregivers provide care for relatives.
- ***Caregivers face many burdens, including:***
  - Sudden changes to financial status;
  - Being unprepared to deal with problem behaviors associated with cognitive impairment of the care recipient;
  - Inability/lack of training to handle specialized care needs (such as lifting, or handling IVs and catheter bags);
  - Lack of time for themselves;
  - Sleep disturbances;
  - Having to make legal and end-of-life decisions;
  - Balancing work and family responsibilities.

### Services and Supports for Caregivers – Putting the Pieces Together

The Older Americans Act, as amended in 2000, established the Title III-E National Family Caregiver Support Program. The program was developed by the US Department of Health and Human Services Administration on Aging. Funds for the program are distributed to designated state units on aging “to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible” (AoA, National Family Caregiver Support Program). The Aging and Long-Term Services Department is New Mexico’s designated state unit on aging.

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AoA funded caregiver services include:

- information to caregivers about available services,
- assistance to caregivers in gaining access to services,
- individual counseling,
- organization of support groups,
- caregiver training,
- respite care, and
- supplemental services.

Nationally, in FY 2007, caregiver funding of \$156,167,000 enabled states to serve 686,030 caregivers. Data from a national survey of caregivers of elders, conducted by the US Administration on Aging, shows:

- 57 percent of caregivers report that services definitely enabled them to provide care longer than otherwise would have been possible, and 77 percent reported that the services “helped a lot”;
- Nearly half the caregivers of nursing home eligible care recipients indicated that the care recipient would have been unable to remain at home without the support services.

### **The New Mexico Aging Network Family Caregiver Service Delivery System**

#### ***Older Americans Act Title III***

The Aging and Long-Term Services Department receives an annual allotment of funds under Title III of the Older Americans Act, as amended, from the US Department of Health and Human Services Administration on Aging. In New Mexico, these funds are allocated to four of the six Area Agencies on Aging [AAAs] based on an approved intrastate funding formula. The area agencies contract with Aging Network providers, statewide, to deliver senior center services, congregate and home delivered meals, in-home support, transportation, legal services, health promotion, respite, adult day care and the like. Significant state funds also support these services. This array of supportive services can be accessed by family caregivers throughout the state.

**“By the year 2030,  
the 65+  
population is  
expected to  
double to 70  
million people.”  
(Family Caregiver  
Alliance,  
Caregiving.)**

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### ***Aging Network Funding and Service Delivery – Title III E***

The Aging and Long-Term Services Department received National Family Caregiver Support Services Title III-E funding in the amount of \$876,111 for FY10 (2009-2010). These funds, along with other

Title III federal funds and state funds are distributed to Area Agencies on Aging (AAAs), which contract with local Aging Network providers, statewide, to deliver services and supports to elders and persons living with disabilities.

**The City of Albuquerque Department of Senior Affairs provides an innovative, evidence-based program called STAR-C, an in-home behavioral intervention program that helps decrease depression and anxiety in individuals with Alzheimer’s disease and their family caregivers. It consists of 8 weekly sessions followed by 4 monthly telephone calls from community-based mental health practitioners.**

- **The City of Albuquerque/Bernalillo County AAA**

According to its 2008-2012 Area Plan, the City of Albuquerque/ Bernalillo County AAA provides services and resources to caregivers through its Senior Information Program, known as Caregiver Connections. The program assists caregivers in obtaining access to training, education and support group resources. Current information and resources are provided, as well as the opportunity to attend a caregiver conference held each year in November. (See attached New Mexico map for service types.)

- **The Non-Metro AAA**

The 2008-2012 Area Plan for the Non-Metro AAA states that Family Caregiver Support Services Program providers offer information, assistance in accessing services, counseling, support groups, training, respite care, and supplemental services (such as home modifications, vouchers for incontinence supplies, nutritional supplements, and assistive devices). The area agency employs an Alzheimer’s/Caregiver Education Coordinator to provide information and assistance to caregivers, statewide, and to coordinate the Alzheimer’s Disease

Supportive Services Program. (See attached New Mexico map for service types by county.)

- **The Indian AAA:**

The 19 Pueblos and 2 Apache Tribes served by the Indian AAA receive OAA Title VI, Part C, Native American Caregiver Support Program funding directly from the federal government. This funding is used to provide caregiver services, respite, information and referral, and case management services. State funds for adult day care also support this array of services. Currently, tribal adult day care centers are provided by the Pueblo of Isleta, the Pueblo of Zuni, and the Mescalero Apache Tribe; a center is being developed by the Santa Clara Pueblo. (See attached New Mexico map for service types by county.)

- **The Navajo AAA:**

The Navajo AAA receives OAA Title III-E funds for Family Caregiver Services from the State of Arizona, and OAA Title VI, Part C, Native American Caregiver Support Program funding directly from the federal government. The Navajo Nation provides respite, information and referral, and caregiver training. (See attached New Mexico map for service types by county.)

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### ***NM Chapter of the Alzheimer’s Association – State Funds***

The Chapter receives state funds awarded through the Aging and Long-Term Services Department. The funds are used to provide information and assistance, consultation and education, support groups, respite vouchers and other supportive services for caregivers. The Chapter has regional offices throughout the state and manages Project Lifesaver and Safe Return Home programs. All of these services are targeted to those who provide caregiving to loved ones with Alzheimer’s disease or other dementias. (See attached New Mexico map for service types by county.)

### **SFY 09 (Caregiver Data, Area Agencies on Aging (PSAs 1,2,3,4 and Alzheimer’s Association)**

<b><u>Unduplicated Consumers</u></b>	<b><u>Service</u></b>
<b>1,119</b>	<b>Respite Care</b>
<b>325</b>	<b>Adult Day Care</b>

### ***Senior Corps – Senior Companion Program – State Funds***

Another family caregiver service component in New Mexico is the Senior Companion Program, administered in cooperation with the Corporation for National and Community Service, Senior Corps. The Aging and Long-Term Services Department provides state funds in the amount of \$1,603,113 to 22 federally-sanctioned Senior Companion Programs around the state. The programs enlist volunteers age 60 or older to provide support and assistance to other older adults who have difficulty with daily life skills.

Senior Companions might pay bills, shop for groceries, provide light housekeeping or perform other tasks. Senior Companions usually help two to four clients and work 20 hours a week. Many clients are individuals with Alzheimer’s disease or other dementias. (See attached New Mexico map for service types by county.)

### ***Alzheimer’s Disease Supportive Services Program***

In July 2004, the Department received a three-year Alzheimer’s Disease Supportive Services Program federal grant. The purpose of the award was to enhance and expand New Mexico’s service delivery system for families of individuals with Alzheimer’s disease and related dementias, particularly in underserved rural and tribal communities. The award enabled the Department to provide regional caregiver support services throughout the state, in coordination with area agencies and the NM Alzheimer’s Association. The funding also enabled the development and implementation of respite care, particularly adult day care, in partnership with local and tribal governments, area agencies and local community organizations.

**The NM Alzheimer’s Association provides an evidence-based program, called *Savvy Caregiver*, which includes specialized training for families and caregivers, offered in a 12-hour session, or via training videos. The training includes information about memory loss, as well as practical skills for everyday use by caregivers.**

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In 2007, another Alzheimer's Disease Supportive Services Program grant was awarded to the Department. The goal of this grant project was to improve the capacity of the state's home and community-based long-term care service delivery system to better address the needs and issues of people with Alzheimer's disease and other dementias and their caregivers. Objectives were to: 1) build Alzheimer's disease technical expertise at the state, area agency, provider and consumer levels; 2) strengthen data collection, integration and integrity; and 3) strengthen options for evidence-based, consumer-directed services, especially adult-day care. These objectives were achieved through various state-wide activities and have included the provision of statewide training regarding Alzheimer's disease and other dementias for aging network staff and volunteers, other service providers and the general public; the expansion of a state-wide computerized data base; consultation services for adult day care providers regarding dementia care; and dissemination of best practices in evidence-based, consumer directed services. A major outcome of the ADSSP project was the

implementation of two evidence-based caregiver interventions in the state, *Savvy Caregiver* and *Star-C*.

**The Alzheimer's Disease Supportive Services Program provides competitive awards to states to expand the availability of community-level supportive services for persons with Alzheimer's Disease and related disorders and their caregivers. In collaboration with the Aging Network and a variety of state and community-level partners, the Program supports efforts to create and maintain responsive, integrated, and sustainable service delivery systems for persons and families impacted by dementias across the United States.**

### ***ALTSO PAC Aging Network Subcommittee Alzheimer's/Caregiver Workgroup***

The Aging Network Subcommittee of the Department's Policy Advisory Committee created an Alzheimer's Disease/Caregiver Workgroup, as a component of the Alzheimer's Disease Supportive Services Program grant project. The activities of this workgroup are as follows:

1. Review of regulations, utilization and needs assessment data, and policies and procedures to make recommendations that support continued development of dementia capable long-term care services.
2. Strategic planning and reporting regarding family caregiver issues with special focus on Alzheimer's disease and other dementias.
3. Monitoring and assessing current trends, activities, and public policy issues that will affect the long-term care system and making recommendations for both systems change and legislative advocacy to address issues.
4. Identifying, coordinating and supporting expansion of evidence-based and consumer-directed family caregiver support programs and services in New Mexico, especially in relation to the federal Administration on Aging's Choices for Independence Initiative.

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Two issue papers, which follow at the end of this report, were developed by the workgroup; one concerns family caregiving, the other, Alzheimer's disease. The PAC workgroup also indicated an interest in conducting strategic planning in regard to caregiving and Alzheimer's disease related issues and recommended including information regarding Alzheimer's disease and caregiving in the Department's strategic plan and in its 2009-2013 State Plan. This report is also a component of the strategic planning activity.

### ***ALTSD Internal Alzheimer's Disease/Caregiving Work Group***

An internal ALTSD workgroup, made up of representatives from each Divisions of the Department was also formed. The purpose of this group is to:

1. Facilitate communication and coordination of resources, education, training, and technical assistance for all staff and volunteers;
2. Identify barriers that may face persons with Alzheimer's disease and other dementias and their caregivers as they access the services and supports available through the ALTSD and identify possible strategies to address identified barriers.

### ***Other Services Provided through ALTSD***

ALTSD administers many other services and programs that offer support to family caregivers:

- The Aging and Disability Resource Center
- Home and Community-Based Services, including Coordination of Long-Term Services (CoLTS), the Disability and Elderly Waiver Program, the Personal Care Option Program, the Program of All-inclusive Care for the Elderly (PACE), the Traumatic Brain Injury Program, the Mi Via Self-Directed Waiver Program and the Gap Program
- Community Advocacy Services including Health Insurance and Benefits Counseling, Prescription Drug Assistance, Money Management and HIV Advocacy
- Long-Term Care Ombudsman
- Adult Protective Services
- Legal Services
- Geriatric Behavioral Health Services
- Faith-Based and Community Initiatives

### **Community and National Organizations**

Many community organizations provide services and supports to family caregivers, such as home health agencies, Meals-on-Wheels, health and wellness programs, and the like. Many national organizations also provide caregiver information and support, such as the AARP, Family Caregiver Alliance, and the National Alliance for Caregiving. (See Resource list at end of document)

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### **NM Direct Caregivers Coalition**

The NM Direct Caregivers Coalition was created to enhance and promote family and professional direct care workers, support professional development and advance issues of importance in the field of long-term direct care. The Coalition defines a caregiver as anyone who serves elders or persons with disabilities.

### **Service Delivery Considerations**

Several studies have shown an underutilization of services by caregivers. Caregivers typically do not know where to turn for information and assistance. Underutilization of services is particularly prevalent among minority and rural caregivers. “Minority groups have more cultural emphasis on caring for their own people. Caregiving is described most often as a source of personal satisfaction and emotional fulfillment, as a result of helping family members in their time of need, fulfilling cultural norms, and bringing family members closer together” (Scharlack, Kellam, Ong, Baskin, Goldstein & Fox, 2006). They are typically “low users of formal support services” because:

- They lack of knowledge about services
- They may mistrust “outsiders”
- Services are unavailable or inappropriate (not culturally or linguistically competent)
- In some cases, services are unaffordable
- They have had negative prior experiences with services
- They feel it is inappropriate to ask for assistance, as it is their responsibility to care for their loved one

**“Only four in ten (41%) say their care recipient received paid services from an aide or nurse, hired housekeeper, or other people paid to help the care recipient . . . .”**  
**(The National Alliance for Caregiving and AARP report, 2004.)**

Developing culturally competent services is critical as, “the elderly population is becoming more racially and ethnically diverse; minority elders are increasing at a rate faster than the majority white elderly population” (Lum, 2005). According to the Alzheimer’s Association, “by the year 2050, 1 in 4 Americans will be of Hispanic origin, and Hispanics develop symptoms of Alzheimer’s up to 7 years earlier than non-Hispanic Caucasians” (Alzheimer’s Association, *Serving Hispanic Families*). Caregiver services that meet the unique needs of Hispanic families are especially critical as “Hispanic frail elders are more likely to receive care from spouses and family members” (Lum).

### **The utilization rate among rural caregivers is also very low, as they:**

- Often do not know they are eligible for services,
- May be unaware that such programs exist in their communities,
- Do not have services readily available in their immediate areas,

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- Have inadequate transportation,
  - Lack telephone and internet connections,
  - Are reluctant to seek assistance unless there is a crisis
- (Buckwalter & Davis, as cited in Butler, 2005)

### **Current Federal Regulations**

#### ***Family Medical Leave***

The Federal Family and Medical Leave Act (FMLA) of 1993 states – “Covered employers must grant an eligible employee up to a total of 12 workweeks of unpaid leave during any 12-month period for one or more of the following reasons:

- for the birth and care of a newborn child of the employee;
  - for placement with the employee of a son or daughter for adoption or foster care;
  - to care for an immediate family member (spouse, child, or parent) with a serious health condition;
  - to take medical leave when the employee is unable to work because of a serious health condition”
- H.R. 4986, the National Defense Authorization Act for FY 2008 (NDAA) amends the FMLA to permit “a spouse, son, daughter, parent, or next of kin” to take up to 26 workweeks of leave to care for a “member of the Armed Forces, including a member of the National Guard or Reserves, who is undergoing medical treatment, recuperation, or therapy, is otherwise in outpatient status, or is otherwise on the temporary disability retired list, for a serious injury or illness.” The NDAA also permits an employee to take FMLA leave for “any qualifying exigency arising out of the fact that a spouse, son, daughter, or parent of the employee is on active duty (or has been notified of an impending call or order to active duty) in the Armed Forces in support of a contingency operation”.

#### ***Federal Legislation Introduced***

Legislation introduced in 2009-2010 includes bills such as: the Elder Caregiver Support and Information Enhancement Act, the Social Security Caregiver Credit Act, the Alzheimer’s Family Assistance Act, the Family Leave Insurance Act, the Caring for an Aging America Act, and several others providing support and services to Veterans and their caregivers.

- ***New Mexico State Legislation*** All bills were postponed indefinitely
- 2005 and 2007—Senate Bills 449 and 597 entitled “The Family Leave Act” were introduced in New Mexico legislative sessions
  - 2007 and 2009—Senate Bills 589 and 570 entitled “Family Medical Leave Employer Tax Credit” were introduced in New Mexico legislative sessions

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### Implications

As the population of New Mexico ages, the numbers and needs of family caregivers will increase. The number of people with Alzheimer's disease and other dementias will also increase as more people live past their 85<sup>th</sup> birthday. The future impacts of these issues are detailed in the Issue Papers at the end of this report. It is urgent to identify, understand and plan for the needs of this burgeoning population.

### Behavioral Risk Factor Surveillance System (BRFSS)

BRFSS was established in 1984 by the Centers for Disease Control and Prevention; currently data is collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. More than 350,000 adults are interviewed each year. States use BRFSS data to identify emerging health problems, establish and track health objectives, and develop and evaluate public health policies and programs. Many states also use BRFSS data to support health-related legislative efforts.

In 2005, the Centers for Disease Control and Prevention funded research at the University of Florida to develop a public health plan for understanding caregiving at a population level. Years of caregiving research has provided deep and detailed information about the risks and benefits associated with providing care to older adults and to people with specific health conditions like heart disease or dementia, or children with special healthcare needs. However, little information has been available about caregivers at a state or national level, including numbers of caregivers.

The University of Florida research team worked with national experts and stakeholders to identify aspects of caregiving that could be compared with public health survey data. The researchers used previous surveys and experience to develop a set of questions—the Caregiver Module—for use with the Behavioral Risk Factor Surveillance System.

Another set of questions on cognitive impairment is being developed for 2010. States that include these questions in the BRFSS surveys will have the information they need to develop and deliver essential services to the growing number of family caregivers and those caregivers coping with Alzheimer's and other dementias.

**The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984.**

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### **Recommendations**

The 2009-2013 New Mexico State Plan for Aging and Long-Term Services contains objectives and activities surrounding Aging Network services and supports for caregivers and for persons with Alzheimer's disease and dementia. The Department's Policy Advisory Committee Alzheimer's Disease/Caregiver Workgroup supports the implementation of the objectives and activities contained in the plan. Further recommendations include:

#### ***Planning***

- Add the Caregiver and Cognitive Impairment Modules to the New Mexico Behavioral Risk Factor Surveillance System (BRFSS).
- Develop an annual Caregiving Report to include updated statewide caregiving data, emerging needs and progress on objectives.
- Expand the mission of the ALTSD Policy Advisory Committee Alzheimer's Disease/Caregiver Workgroup to include facilitation of the development of state-wide planning for dementia.

#### ***Advocacy***

- Include caregivers on policy-making and decision-making boards – in government, the health care industry, and at the workplace.
- Explore the possibility of reintroducing state legislation regarding tax credits for caregivers.
- Support innovative strategies to finance long-term care, such as those identified at the 2001 Caregiver Empowerment Summit, including:
  - a mix of subsidized insurance, private insurance, tax credits and deductions;
  - stipends for family caregivers who choose to provide care themselves;
  - Social Security credits to those who leave the workplace to provide full-time caregiving;
  - development of caregiver ombudsmen, caregiver registries, caregiver joint purchasing arrangements, and care management services;
  - implementation of a pool of trained paid caregivers large enough to meet the growing need.

#### ***Implementation***

- Include topic specific links for caregiver resources and assistance on aging network websites.
- Support the development of community caregiver coalition projects around the state. (A model for this could be Georgia's CARE-NET, a collaborative network of representatives from a variety

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of constituencies, including family care providers, area agencies on aging, educational institutions, businesses, and other interested groups.)

- Ensure that all service components are culturally and linguistically appropriate and meet the unique needs of rural populations.
  - Establish family caregiving coaches and a 24-hour hotline for caregivers.
  - Partner with community colleges to develop caregiver components for direct service paraprofessional curricula, such as certified nursing assistant training.
- Support expansion of supplemental services options, as funding allows, in each Aging Network Planning and Service Area.

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### INTERNET SITES

#### *National Internet Sites*

- AARP Foundation  
([http://aarp1.convio.net/site/PageServer?pagename=signup\\_caregiving\\_guide](http://aarp1.convio.net/site/PageServer?pagename=signup_caregiving_guide))
- AARP.org (<http://www.aarp.org/family/caregiving>)
- Administration on Aging, National Family Caregiver Support Program  
([http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx))
- Administration on Aging, Title VI Native American Programs  
(<http://www.olderindians.org/>)
- Caregiver Resource network ([www.caregiverresource.net](http://www.caregiverresource.net))
- Caregiving.com ([www.caregiving.com](http://www.caregiving.com))
- Family Caregiver Support Network (<http://caregiversupportnetwork.org>)
- Family Care Resource Connection/Clearinghouse (<http://www.caregiving.org/resources/>)
- Full Circle of Care, Hands on Help for Family Caregivers (<http://www.fullcirclecare.org/>)
- The Caregiver Resource Center ([www.caregiverresourcecenter.com](http://www.caregiverresourcecenter.com))
- The Center for Rural Health, Univ. of N. Dakota, National Resource Center on Native American Aging (<http://ruralhealth.und.edu/projects/nrcnaa/servicelocator.php>)
- The National Alliance for Caregiving (<http://www.caregiving.org/resources/>)
- The National Alzheimer's Association (<http://www.alz.org>)
- The National Center on Caregiving at Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org))
- The National Family Caregivers Association ([www.thefamilycaregiver.org/](http://www.thefamilycaregiver.org/))
- The National Institute on Aging(NIA) (<http://nihseniorhealth.gov/medicare/toc.html>)
- USA.gov ([www.usa.gov/Citizen/Topics/Health/caregivers.shtml](http://www.usa.gov/Citizen/Topics/Health/caregivers.shtml))

#### **Resources/Services Provided** (the list is not all inclusive):

- Educational brochures/factsheets
- Newsletters/ publications
- Tip and tools on caregiving
- Caregiver info and advice
- Information on government benefits, legal matters and end-of-life issues
- Information on events such as conferences, training sessions (i.e. "Cluster Training that will focus on the Native American Family Caregiver Support Program)
- On-line workshops
- Long-distance caregiving
- Related advocacy/ legislation
- Support/respite resources, including information on adult day care

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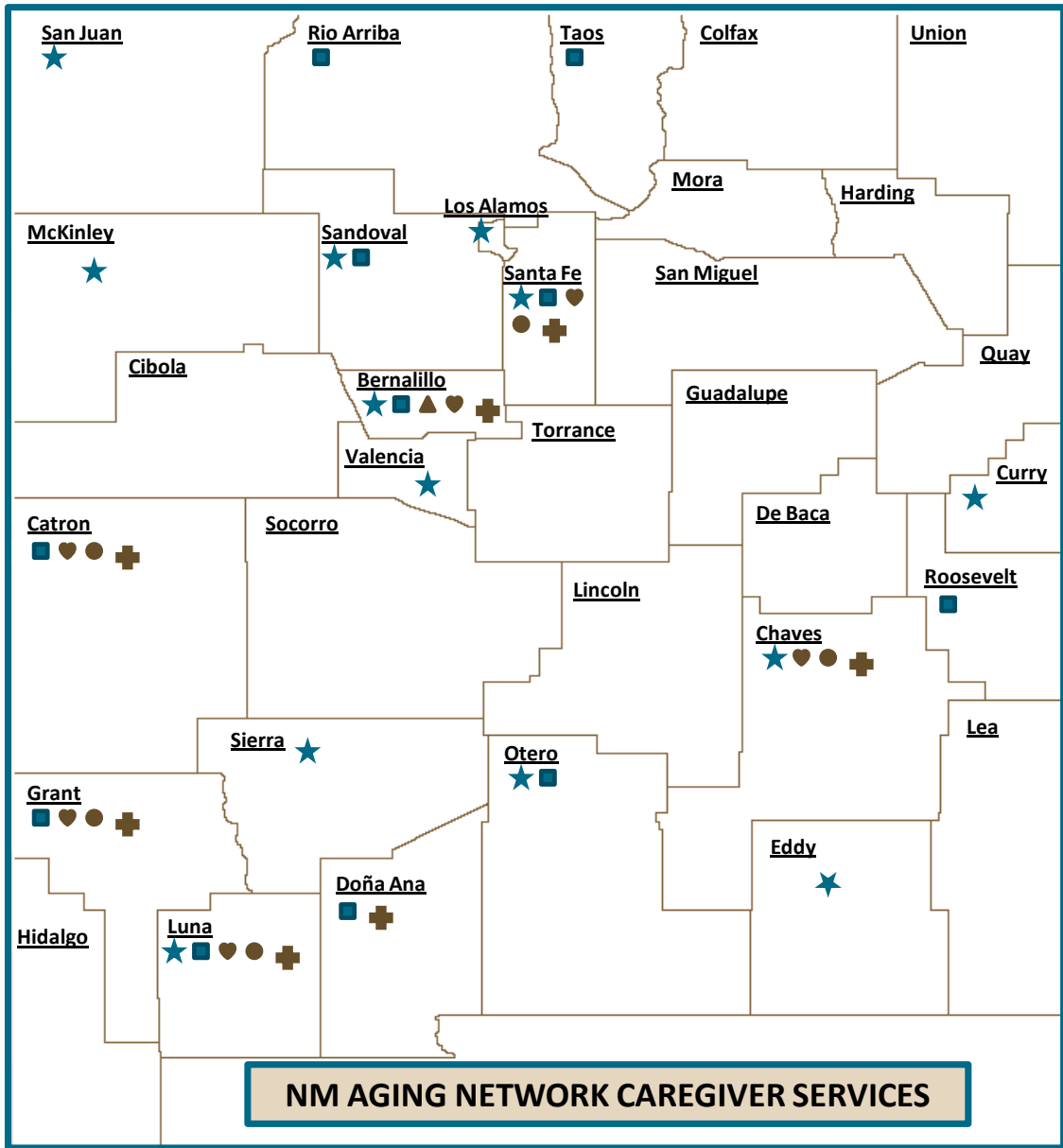
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### INTERNET SITES CONTINUED

- On-line support groups (i.e. Pen Pal - connection to other caregivers), and/or info on local support groups around the country
- Web-links to other caregiver organization such as the Family Care Resource Connection/Clearinghouse (<http://www.caregiving.org/resources/>)
- Fee for service resources: assessments, development of individualized care plans, professional referrals, information & referral, monitoring/advocacy for long-distance caregivers, consultation, counseling
- Overview of Medicare benefits and resources (NIA)

### *New Mexico Internet Sites*

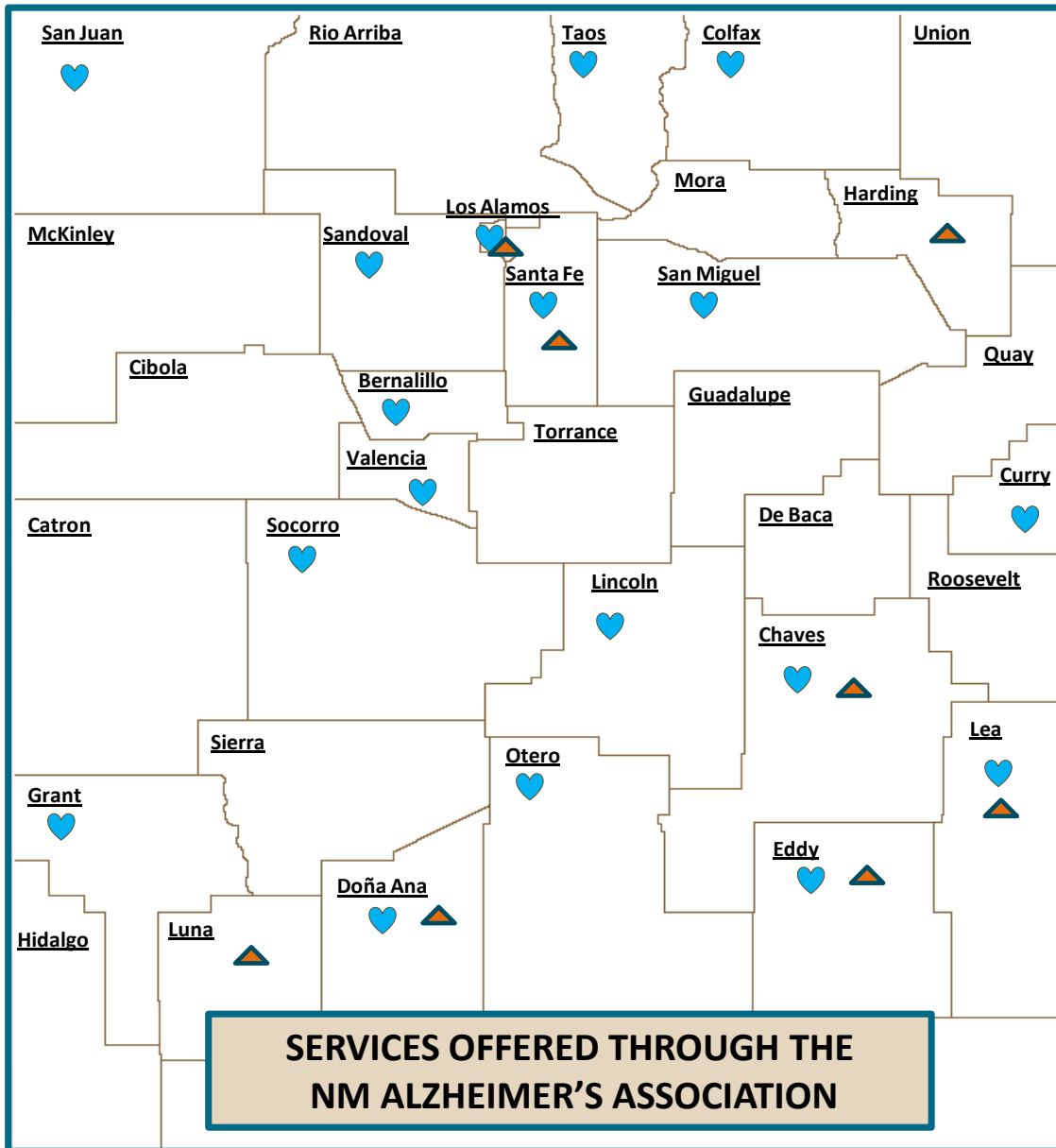
- The Aging and Long-Term Services Department (ALTSD) website ([www.nmaging.state.nm.us](http://www.nmaging.state.nm.us))
- Aging Network (statewide) providers (links accessed through AAA websites)
- The City of Albuquerque/Bernalillo County Area Agency on Aging (AAA) (<http://www.cabq.gov/seniors/index.html>)
- The Department of Health/ALTSD Social Services Resource Directory ([www.nmresourcedirectory.org](http://www.nmresourcedirectory.org))
- The Indian Area Agency on Aging (IAAA) – no website available, but contact info for Pueblos, Mescalero Apache Tribe and Jicarilla Apache Tribe can be obtained from the IAAA office ([Ray.Espinoza@state.nm.us](mailto:Ray.Espinoza@state.nm.us), 505 **476-4698**) and/or on the website for The Center for Rural Health, Univ. of N. Dakota, National Resource Center on Native American Aging (<http://ruralhealth.und.edu/projects/nrcnaa/servicelocator.php>)
- The Navajo Area Agency on Aging (<http://www.naaa.navajo.org/>)
- The Non-Metro Area Agency on Aging (<http://www.ncnmedd.com/aaa.html>)
- The NM Chapter of the Alzheimer’s Association (<http://www.alz.org/newmexico/>)



**Map 1**

- ★ Adult Day Care/ Health:  
Los Alamos, Chaves, Otero, Bernalillo, Eddy, Gallup, Sandoval, Santa Fe, Curry, Luna, San Juan, Sierra, Valencia
- Respite (In-Home):  
Rio Arriba, Taos, Sandoval, Santa Fe, Doña Ana, Catron, Roosevelt, Grant, Otero, Luna, Bernalillo
- ♥ Counseling:  
Bernalillo, Catron, Chaves, Grant, Luna, Santa Fe
- Supplemental Services:  
Catron, Chaves, Grant, Luna, City of Santa Fe
- ⊕ Access Assistance:  
Doña Ana, Catron, Chaves, Grant, Luna, Santa Fe, Bernalillo
- ▲ STAR-C Program :  
Bernalillo

Information and Referral:  
City of Albuquerque / Bernalillo County AAA  
Non-Metro AAA - **Statewide**



**Map 2**

Caregiver Support Groups:  
Bernalillo, Chaves, Colfax, Curry, Doña Ana, Eddy, Grant, Lea, Lincoln, Los Alamos, Otero, San Juan, San Miguel, Sandoval, Santa Fe, Socorro, Taos, Valencia

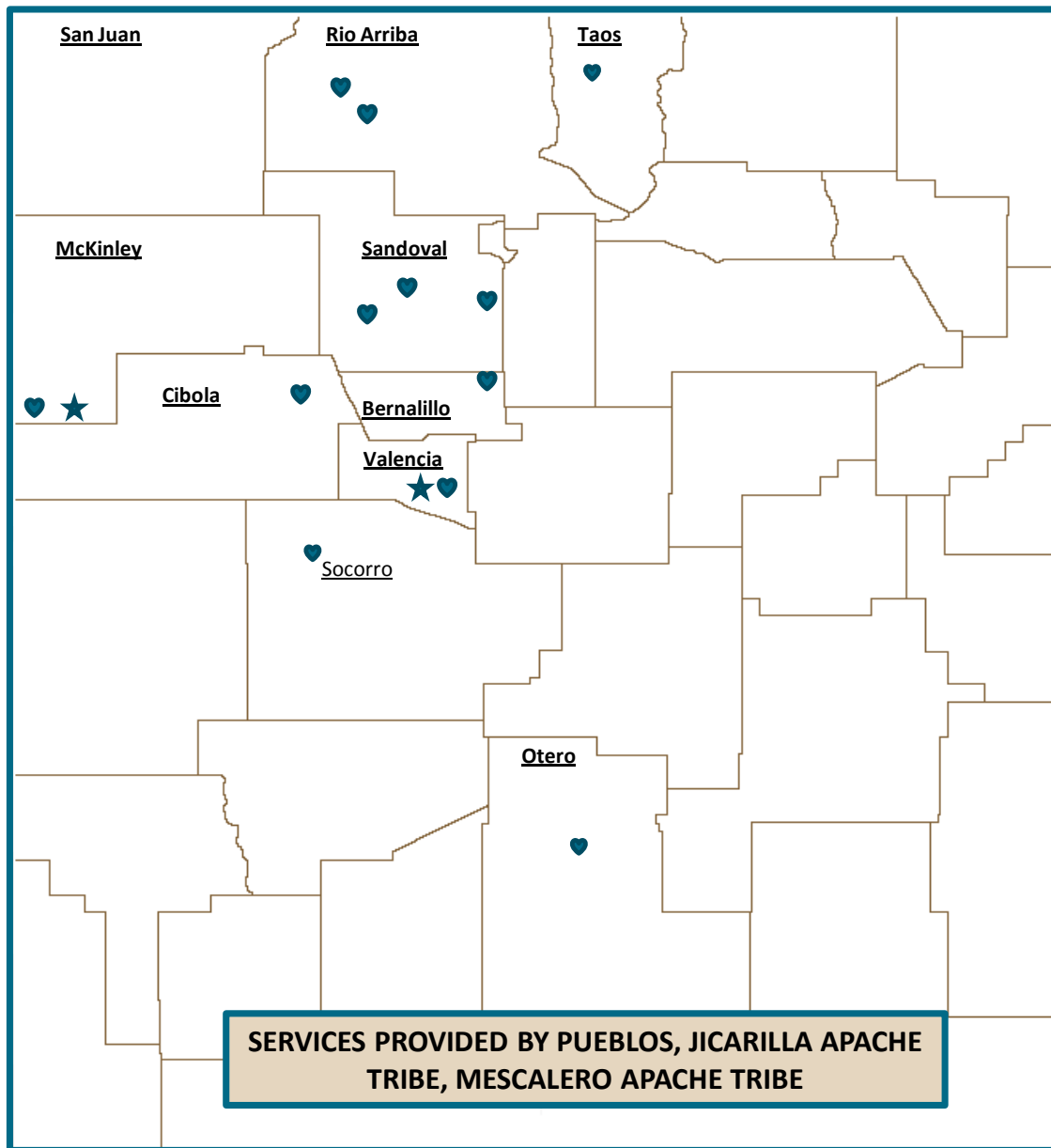
Project Lifesaver:  
Lea, Harding, Chaves, Doña Ana, Los Alamos, Santa Fe, Eddy, Grant

MedicAlert®  
+ Alzheimer's Association Safe Return®:  
**Statewide**

Caregiver Training, including Savvy Caregiver:  
**Statewide**

Toll-free Helpline Assistance:  
**Statewide**

Respite vouchers:  
**Statewide**



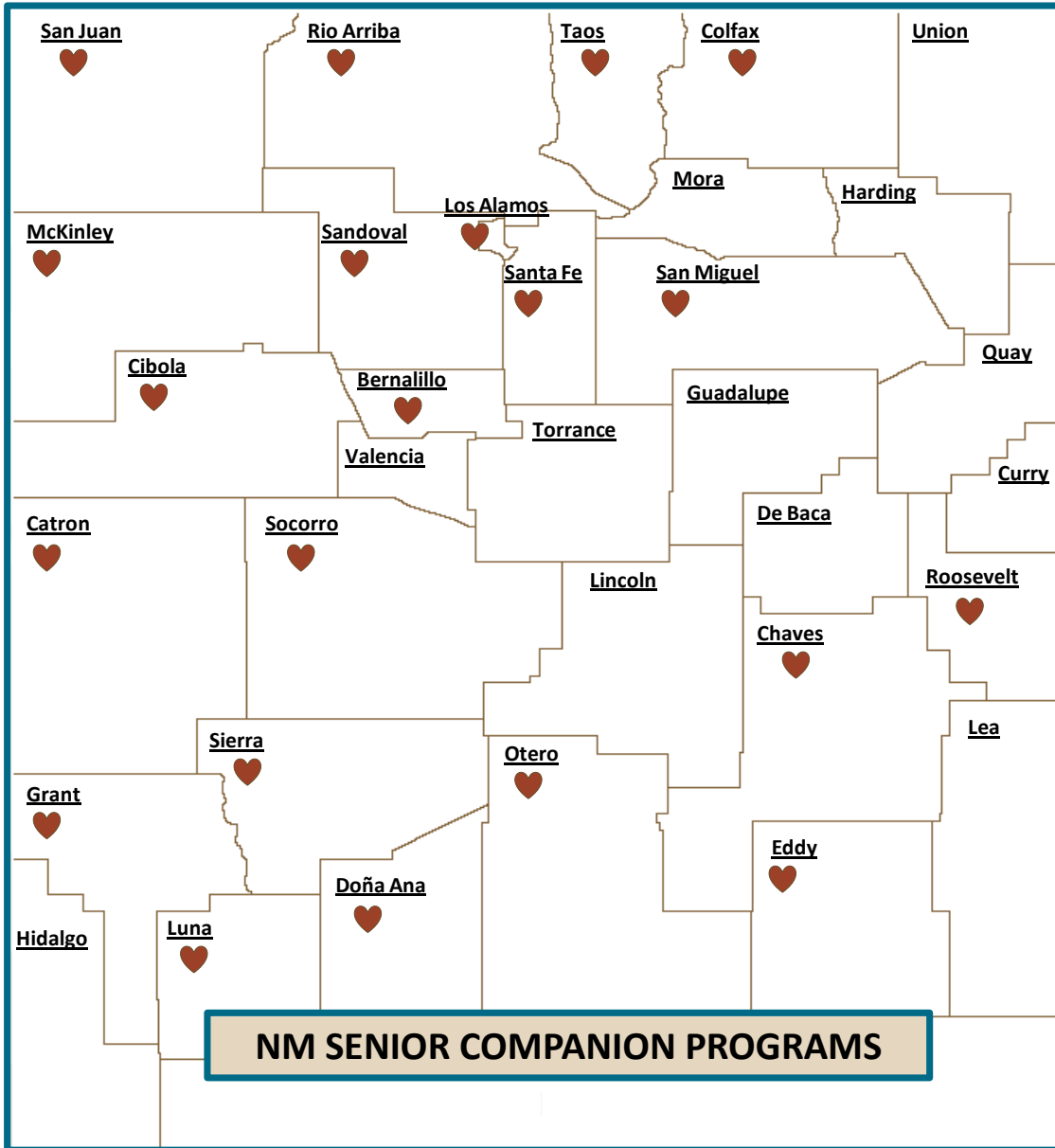
**Map 3**

- ♥ \* Caregiver Services: Jicarilla Apache, Taos, Cochiti, Eight Northern Indian Pueblos Council, Jemez, San Felipe, Santo Domingo, Five Sandoval, Isleta, Acoma, Laguna, Zuni, Mescalero Apache
- ★ Adult Day Care: Isleta, Zuni

The Pueblos and Tribes also provide services, such as home-delivered meals, in-home support, homemakers and transportation, that support caregivers.

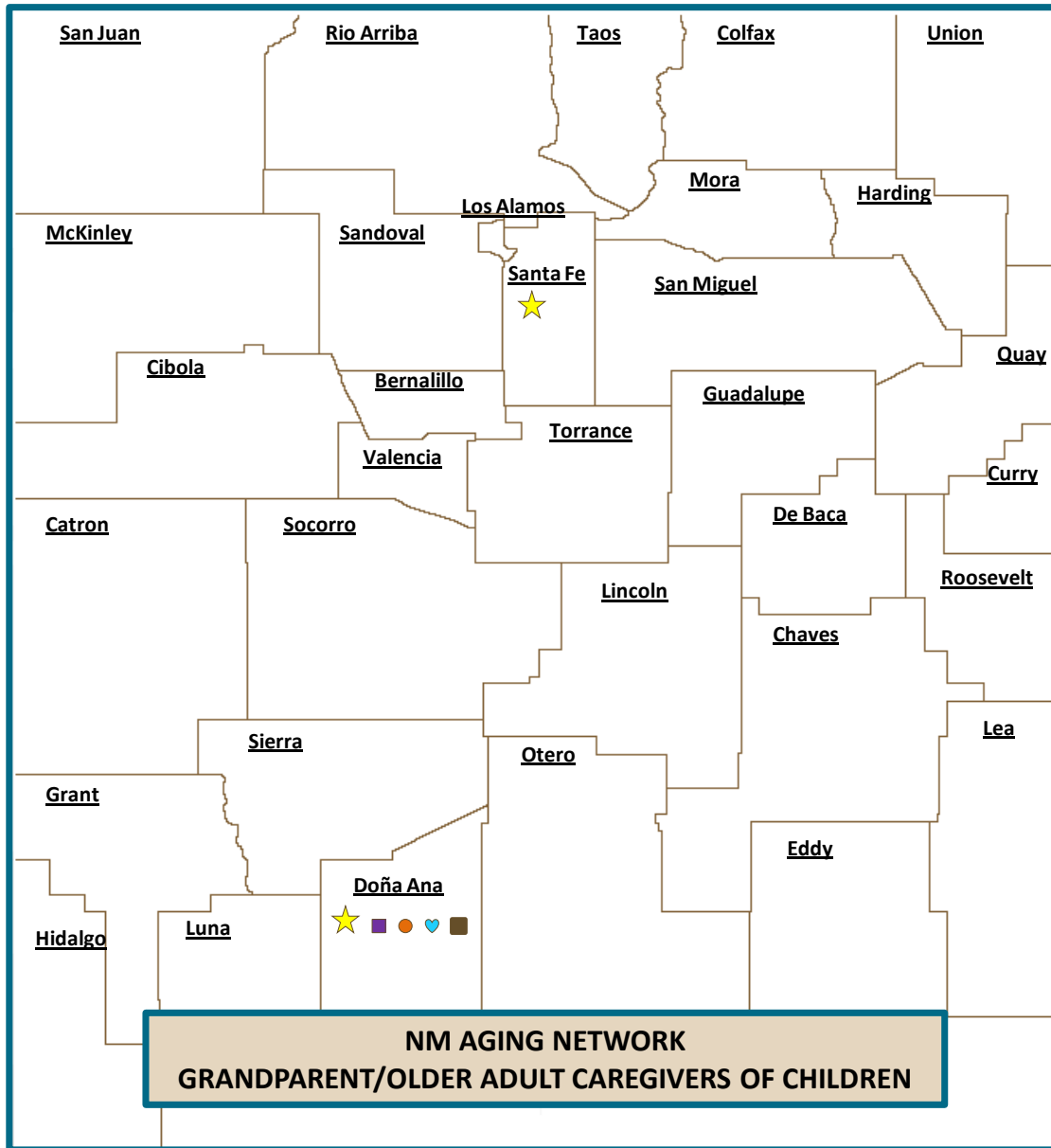
\* Caregiver services are defined as: information & assistance, counseling, support groups, caregiver training, respite, and supplemental services. Please note: not all of these services are provided by each Pueblo or Tribe.

Data on NM Pueblos and Tribes obtained from 2008-2009 AAA Budget Summary by Service, and from the Center for Rural Health, University of North Dakota, School of Medicine & Health Sciences. Data was confirmed by NMALTS Indian AAA Director.



**Map 4**

♥ Companionship / Caregiver Respite:  
 Otero, Bernalillo, Taos, Catron, Chaves, Colfax, Roosevelt, Doña Ana, McKinley, Luna, Rio Arriba, Cibola, Grant, San Juan, San Miguel, Los Alamos, Sandoval, Santa Fe, Socorro, Sierra, Eddy, Pueblo of Zuni (other Pueblos and Tribes are served by the programs listed above)



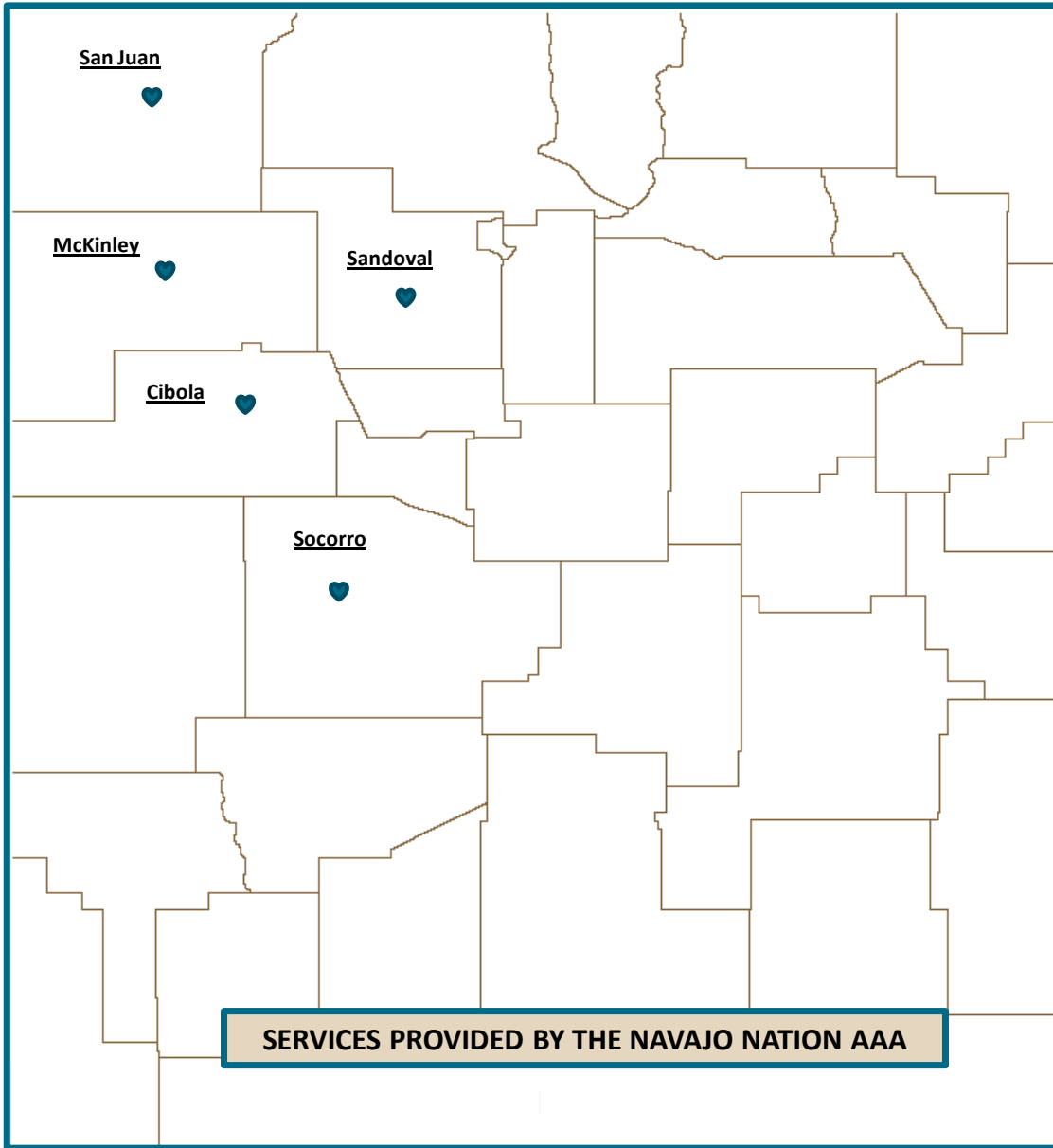
**NM AGING NETWORK  
GRANDPARENT/OLDER ADULT CAREGIVERS OF CHILDREN**

**Map 5**

- ★ Respite (In-Home):  
Santa Fe, Doña Ana
- Respite vouchers:  
Doña Ana
- Information & Access Services:  
Doña Ana
- ♥ Counseling:  
Doña Ana
- \*\*Supplemental Services:  
■ Doña Ana

\*\*School supplies, clothing, household items such as beds, and the like

\*Data taken from 2008-2009 AAA Budget Summary by Service



**Map 6**

♥ Caregiver Services:

Caregiver Training/Education

Information & Referral

Respite

The Navajo Nation AAA also provides services, such as home-delivered meals, in-home support, homemakers and transportation, that support caregivers.

### Policy Advisory Committee, Joie Glenn, Chair

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### OVERVIEW

Informal, unpaid caregivers provide the vast majority of long-term services and supports received by the elderly and persons with disabilities of all ages. These contributions are the foundation of the long-term care system in New Mexico and the rest of the country, with an estimated economic value of \$350 billion nationwide in 2006.

### DATA REGARDING THE ISSUE

- An estimated 200,000 people in New Mexico, or nearly 10% of the population, served as family caregivers in 2006, totaling about 183 million hours of caregiving during the year.
- The estimated economic value of the unpaid care provided by these caregivers in New Mexico is about \$1.6 billion.
- The economic value of this caregiving exceeds total Medicaid spending on long-term care services, including both nursing home and home- and community-based services, according to an AARP study.
- Women comprise about two-thirds of all unpaid caregivers.
- Caregiving for a parent substantially increases a women's risk of living in poverty and receiving public assistance in later life.
- Family members who provide care to individuals with chronic or disabling conditions are at higher risk for health problems, including physical, emotional and mental health issues.
- Elderly spousal caregivers experiencing mental or emotional strain may have a 63% higher risk of dying than non-caregivers.
- A recent study calculated that American businesses lose between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older.
- Caregivers lose an average of \$659,000 in total wealth as a result of caregiving (wages, reduced Social Security benefits, pensions and savings).

- The Older Americans Act provides funding for support services for caregivers without regard to income through the National Family Caregiver Support Program (NFCSP); funding, however, is insufficient to meet the need.
- In a national survey, almost 40% of caregivers surveyed said they didn't know where to call to arrange help in the home for elderly relatives or friends.

#### **ANTICIPATED FUTURE IMPACT OF THE ISSUE**

- The number of elderly and disabled is beginning to outnumber the pool of potential caregivers.
- Workforce shortages of trained workers to assist family caregivers with in-home services are growing.
- Changes in the health care delivery system, such as shorter hospital stays, will further shift the cost and responsibility of the care of elders and those with disabilities to family caregivers.
- Family caregivers whose health is impaired through caregiving will potentially cost the health care and long-term care system more in the future.

#### **ANTICIPATED FUTURE NEEDS**

- A large trained workforce to provide in-home, community support services, to decrease both physical and financial burden on caregivers.
- Increased funding, training, and technical assistance to enhance amounts, types and quality of caregiver support services, including evidence-based support services.
- A dialogue among multiple government agencies, private organizations, health care providers and other stakeholders, to strengthen policies and initiatives that recognize and support family caregivers.
- Improved care coordination across health and social service settings.
- Strategies for mitigating financial burdens of families providing long-term care.

#### **CHANGING ROLE OF ALTSD**

- Development of more caregiver support programs
- Enhanced emphasis on coordination of services and funding streams for caregiver programs and populations served by the Department.
- A focus on balancing the needs of caregivers and the needs of those receiving services.
- Greater attention to access information regarding available caregiving services and supports.
- Data collection regarding the health status of caregivers for future planning and administration of caregiver services.

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### OVERVIEW

The Alzheimer's Association estimates that 40,000 New Mexicans age 65 or older will have Alzheimer's disease by the year 2010. The incidence of Alzheimer's Disease for people over the age of 65 is one in eight; for those over the age of 85, it is nearly 50%. This disease will impact the long-term care service delivery system in New Mexico as the rate of growth of both of these populations is expected to dramatically increase in the next 15 years.

### DATA REGARDING THE ISSUE

- No treatment currently exists that can delay or stop the deterioration of brain cells in Alzheimer's disease. Ultimately, Alzheimer's disease is fatal.
- Alzheimer's disease is progressive. Symptoms of the disease begin with difficulty remembering new information, worsen to confusion, impaired judgment and communication difficulties and deteriorates to loss of abilities to complete daily living activities and loss of recognition of loved ones. Eventually, the individual becomes bed-bound.
- Many people with Alzheimer's disease or other dementias have not been diagnosed.
- Studies have shown that active medical management can significantly improve the quality of life through all states of the disease for diagnosed individuals and their caregivers.
- People with Alzheimer's disease and other dementias often suffer from one or more other chronic illnesses or conditions. Dementia complicates the care for these conditions, and thereby drives up the costs of treatment.
- People with Alzheimer's disease and other dementias are high users of health care, residential care and home and community based services.
- Nearly all people with Alzheimer's disease eventually need more assistance than families and friends can provide, and move into long-term care settings.
- Nationally, 51% of nursing home residents with Alzheimer's disease and other dementias relied on Medicaid to help pay for their nursing home care in 2000.
- Medicaid nursing facilities expenditures for persons with Alzheimer's disease is projected to increase from \$18.2 billion in 2000 to \$33 billion in 2010—an increase of more than 80% in just 10 years.

- Seventy percent of people with Alzheimer's disease and other dementias live at home, where family and friends care for them.
- Because Alzheimer's disease gets worse slowly, caregivers tend to spend a long time in their caregiving role.
- The challenges of caring for a loved one with Alzheimer's disease and other dementias often affect the health and income of the caregiver.

#### **ANTICIPATED FUTURE IMPACT OF THE ISSUE**

- As the population ages, the incidence and prevalence of people affected with this disease will grow commensurately.
- The increased incidence of Alzheimer's disease and other dementias will increase utilization of the long-term care system, including home- and community-based services and nursing homes; this, in turn, will increase the state's Medicaid expenditures.
- Family caregivers will face increased demands that will impact their health and economic situations.
- The long-term care system will encounter continuing challenges in providing supports and services to individuals with cognitive impairments and their family caregivers.

#### **ANTICIPATED FUTURE NEEDS**

- Availability of a dementia-capable workforce, in both home- and community-based and residential services will be critically important.
- Family caregiver support services that are consumer-directed, flexible and can be provided in a quantity that will meet the caregiver's needs must be enhanced.
- Education to assure early identification and diagnosis of the disease so that medical management can be provided is essential.
- Information and referral systems will need to be coordinated, accurate and widely available to assist individuals and family members to receive appropriate services and supports.
- Direct support services for individuals with Alzheimer's disease and other dementia and their family caregivers need to be evidence-based to provide for effective and beneficial results.

#### **CHANGING ROLE OF ALTSD**

- Alzheimer's Disease and other dementias will become more widely integrated within programs and services provided by the department.
- Alzheimer's Disease and other dementias will become recognized and supported as a disease, and not separated from other care needs of the individual.