

# New Mexico State Plan

---

For Family Caregivers



# Letter of Introduction

Caregiving is an essential, if implicit, part of our identity as New Mexicans. When our aging parents need more support, or a spouse or sibling falls ill, helping them comes for many of us as a reflex, rather than a conscious choice.

Each year, more than 20 percent of our population provides unpaid care to a loved one. As our older population expands rapidly through the first part of this century, it is critical that we take a strategic approach to issues of caregiving in our state. These issues promise to have an increasing impact on families, communities, businesses, and government.

The Family Caregiver Task Force was convened by the Aging and Long-Term Services Department in response to this need and pursuant to the passage of House Joint Memorial 4 (HJM 4) in 2014 sponsored by Representative Tomas Salazar. Comprised of more than 50 participants, the task force had broad representation from state government, providers, employers, advocates, tribal organizations, educators, and caregivers themselves. We offer special thanks to AARP New Mexico, which enlisted national public policy experts and funded a statewide caregiving survey to inform the plan before you now.

This task force worked diligently throughout 2014 and 2015 to identify gaps between the current and ideal situations of New Mexico caregivers and to develop strategies for bridging those gaps. Five work groups, addressing family support, training and planning, care coordination, support for working caregivers, and public awareness, developed recommendations that were presented to the full task force for consideration. Along with supporting research and identified best-practices, these are the basis for the plan's goals and strategies.

The *New Mexico State Plan for Family Caregivers* will guide the state in addressing this serious and growing problem. Successful implementation of this plan will require the combined, coordinated efforts of public agencies, private organizations, communities, and families. We urge you to study these ideas, goals, and strategies and to join in partnership to make a difference in the lives of family members, friends, neighbors, and all those who are affected by the challenges of family caregiving. Together, we can support our family caregivers.



Susana Martinez, Governor



Myles Copeland, Cabinet Secretary Designate  
Aging and Long-Term Services Department



# New Mexico State Plan for Family Caregivers



Section		Page
I.	Letter of Introduction	
II.	Executive Summary	5
III.	Process	7
IV.	Family Caregiving in New Mexico	9
	-Scope and Trends	
	-Caregiving Tasks	
	-Working Caregivers	
	-The Impact of Caregiving	
	-Differences in Rural and Urban Caregiving	
V.	Types of Caregiver Supports	14
	-Care Coordination	
	-Training and Planning	
	-Additional Resources and Supports	
VI.	Goals and Strategies	20
VII.	Conclusion	30



Each year  
**419,000 New Mexicans**  
provide more than  
**274 million hours**  
of unpaid family care

## Executive Summary

The size of New Mexico's family caregiver population is staggering. Approximately one in five New Mexicans serves as a family caregiver during any given year. These individuals play a critical role, not only in helping their loved one, but in assisting a state which would be overwhelmed without them, in terms of both cost and capacity. Family caregivers provide 80 percent of all long-term care. On average, New Mexico's family caregivers provide 18.4 hours of care per week. The total economic value of this care is estimated to be \$3.1 billion annually.

Compared to the pool of likely family caregivers, the number of people needing care will skyrocket through the middle of this century as the baby boomers age. The challenges associated with family caregiving will become increasingly critical. With its broad scope and wide participation, family caregiving has implications for employers, businesses, communities, and local, state, and federal governments.

Family caregivers suffer negative impacts to their physical, psychological, and financial well-being. Several resources and programs currently available in New Mexico aim to improve outcomes for family caregivers. Family caregivers typically arrive at their responsibilities without preparation, not knowing what assistance is available to meet their needs or how to access this assistance. Additional resources, support, respite, and training are needed, as well as a coordinated system for more effectively connecting the legion of family caregivers with this help.

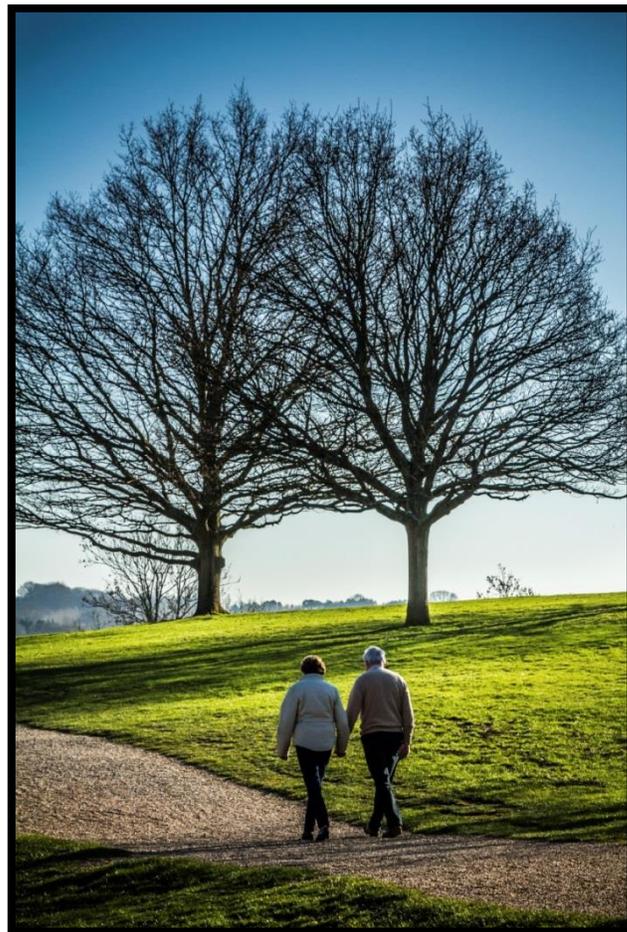
This report presents the findings and recommendations of the New Mexico Family Caregiver Task Force, which was formed in April of 2014, pursuant to New Mexico House Joint Memorial 4 (HJM 4) to create a state plan for addressing the challenges faced by family caregivers.

The task force drew together experts in all aspects of family caregiving, obtained public input, and worked to identify short- and long-term challenges and solutions to meet the needs of New Mexico's family caregivers. The task force deliberations produced this statewide plan, whose implementation promises to maximize the abilities of family caregivers, while providing them with needed assistance.

The following goals are recommended along with strategies for their achievement:

- *Ensure that family caregivers access the resources they need*
- *Ensure that family caregivers are properly trained*
- *Limit future caregiver burden*
- *Ensure that family caregivers are supported*
- *Make family caregiving easier through coordination of care*
- *Ensure support for family caregivers who work*
- *Ensure that family caregivers access respite*

Execution of this plan will require coordinated action from public agencies and private organizations in order to mobilize the resources and talent necessary to address the needs of New Mexico's family caregivers.



## Process

In developing the *New Mexico State Plan for Family Caregivers*, the New Mexico Aging and Long-Term Services Department (ALTSD) convened the New Mexico State Family Caregiver Task Force in April of 2014, pursuant to New Mexico House Joint Memorial 4 (HJM 4).

Passed during the 2014 legislative session, HJM 4 focused on the issues of family caregivers providing care to older adults and the task force honored this focus. HJM 4 also named 20 different public agencies, private organizations, and stakeholder groups for inclusion in the task force. Ultimately, more than 50 representatives participated in seven meetings of the full task force, spanning 14 months.

From the outset, the task force adopted four overarching principles to guide its work:

- Address the rural and frontier nature of the state
- Respect and incorporate ethnic and cultural traditions
- Recognize and address the high rate of poverty in the state
- Ensure that recommendations are actionable



To ensure the plan was informed by New Mexico's family caregivers, public input was garnered via three caregiver forums and four ALTSD listening sessions.



Family caregiver surveys were also conducted at outreach events and via the ALTSD website. More than 600 people attended these input events or submitted surveys.

Adding to the task force's understanding of relevant issues, task force partner AARP New Mexico commissioned a caregiving survey. This survey was critical in detailing the demographics, duties, needs, and desired supports of caregivers. Reaching 1,000 of the state's registered voters 45 and older, the survey oversampled rural counties and conducted follow up calls to non-English speaking households to ensure proper representation of these populations.

The task force formed five work groups, each targeting an aspect of family caregiving and charged with identifying needs, current resources for addressing needs, gaps between needs and current resources, and recommendations for addressing such gaps. These work groups focused on the areas of family support, training and planning, care coordination, support for working caregivers, and public awareness.

The reports of these work groups, feedback from the full task force, collected public input, and research were reviewed and synthesized into this plan.

The plan is intended to offer guidance, not only to state government, but to all public agencies, private organizations, and stakeholders interested in addressing the direct and indirect challenges of family caregiving in New Mexico.

# Family Caregiving in New Mexico



## *Scope and trends*

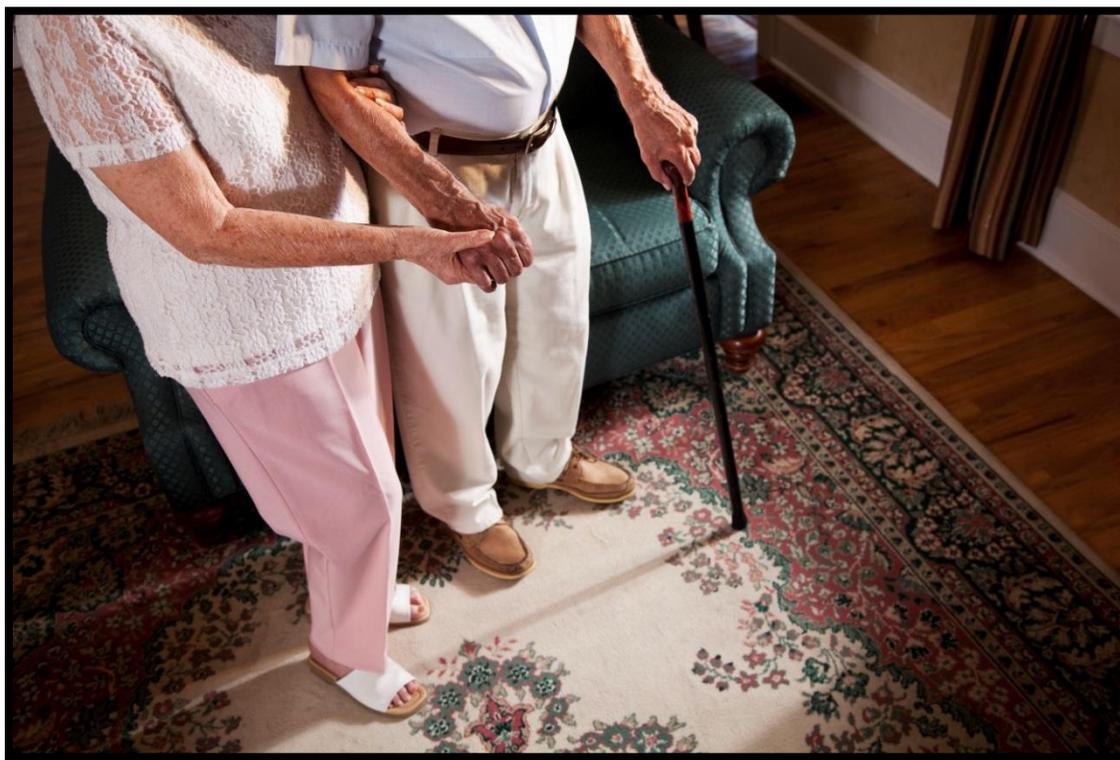
The size of New Mexico's family caregiver population is staggering. Annually, 419,000 New Mexicans provide unpaid care to adults with limitations in daily activities, such as mobility, self-feeding, and dressing, with 287,000 providing care at any given time during the year.<sup>i</sup> Though these caregivers include friends and neighbors as well as relatives, all people providing unpaid care will be referred to as "family caregivers" for purposes of this report.

On average, New Mexico's family caregivers provide 18.4 hours of care per week. The total economic value of this care is estimated to be \$3.1 billion annually.<sup>ii</sup> Nationally, family caregivers provide 80 percent of long-term care.<sup>iii</sup>

Trends indicate that New Mexico's demand for family caregivers will continue to increase. The average age of care recipients was 80 in a 2014 New Mexico survey funded by AARP.<sup>iv</sup> The state's 80 and older population is projected to grow 80.5 percent between 2015 and 2030.<sup>v</sup> With fast growth in the segment of the population most in need of care, demand for family caregivers is likely to rise.

As the number of Americans needing care climbs through 2050, the ratio of people available to care for them declines. The typical caregiver is a 46-year-old woman providing care to her mother.<sup>vi</sup> Describing the looming challenge of caring for the United States' baby boomers as they age, AARP's public policy researchers define the caregiver support ratio as "the number of potential caregivers between the ages of 45-64 for each person aged 80 and older." This ratio stood at seven potential caregivers for every person 80 or older in 2010, but will decline to 4 to 1 by 2030 and 3 to 1 in 2050.<sup>vii</sup>

Women still do most of the family caregiving. Among all family caregivers, 60 percent are female.<sup>viii</sup>



Nationally, the prevalence of caregiving varies by racial/ethnic group and is higher than average among Hispanics. A 2015 report conducted by the National Alliance for Caregiving and AARP estimated that 21 percent of Hispanics serve as family caregivers, compared with 16.9 percent of non-Hispanic whites.

The prevalence of caregiving in the Native American population is also greater than that of the general U.S. population.<sup>ix</sup> Family members provide an estimated 90 percent of long-term care in Indian country,<sup>x</sup> yet there has been little research about these caregivers, the people they care for, or their need for assistance and support. Census data shows the number of Native Americans aged 75 years or older who will need long-term care will double in the next 25 years.<sup>xi</sup> This situation is further complicated by out-migration from reservations, which seems likely to leave a smaller pool of prospective caregivers.<sup>xii</sup>

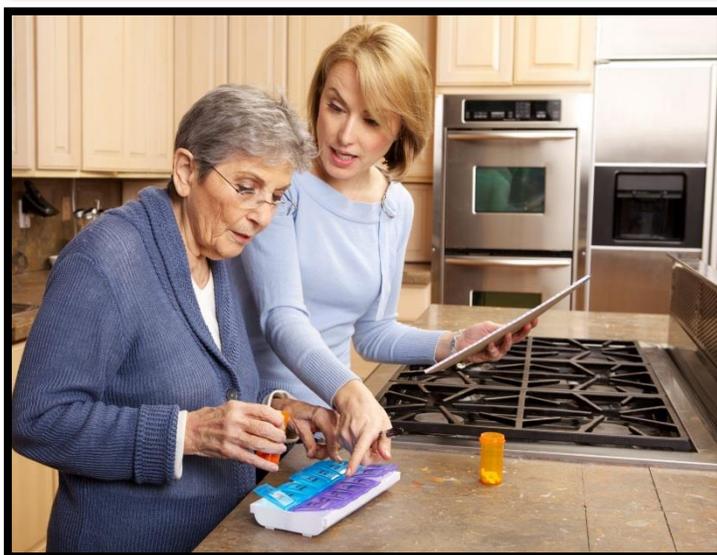
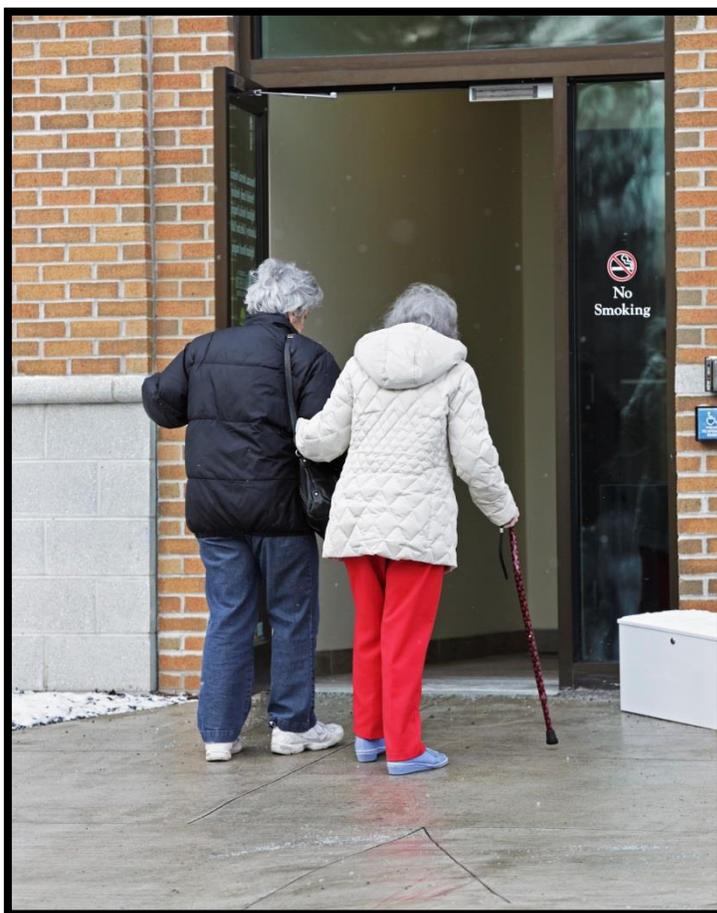
## Caregiving tasks

Family caregivers perform a variety of tasks in response to the needs of care recipients. As the independence of a loved one decreases with age or illness, dependence upon outside supports, primarily family caregivers, increases. When asked which types of care they provided, a majority of New Mexicans who identified themselves as current or former caregivers indicated a multitude of tasks.

Each of the following supports had been provided by more than 52 percent of respondents: shopping (92%), transportation (90%), chores (88%), meals (87%), medication management (74%), financial management (69%), medical tasks (71%), and assistance with bathing or dressing (53%).<sup>xiii</sup>

The sheer number of tasks a family caregiver must perform may be daunting, and many family caregivers find themselves with medical duties for which they may not have been sufficiently trained. Nationally, 46 percent of caregivers are providing medical or nursing tasks, such as wound care and operating specialized medical equipment.<sup>xiv</sup>

These task types were especially common among New Mexico's family caregivers, with 71 percent indicating they had been responsible for medical or nursing tasks and 74 percent indicating they had overseen medication management.<sup>xv</sup>



Not only are family caregivers performing numerous tasks, but many are addressing the needs of more than one care recipient. About one-third of caregivers nationally provide assistance to more than one person and about one in ten provides assistance to three or more people.<sup>xvi</sup>

### *Working caregivers*

Most family caregivers work and caregiving affects their work. Nationally, 74 percent of adults with eldercare responsibilities have worked at some point during their caregiving experience.<sup>xvii</sup> In AARP New Mexico's caregiving survey, 57 percent of current and former caregivers reported having been employed full- or part-time while providing care. This statistic likely varies from the national average because respondents were 45 and older.



Among these respondents, 69 percent reported having to alter their work schedule or take time off, 34 percent said they had taken a leave of absence, and 24 percent said they had to go from working full-time to part-time to provide care.<sup>xviii</sup>

During each of the caregiver forums conducted as part of the New Mexico family caregiver task force process, audience members detailed their difficulties in balancing work and caregiving responsibilities.

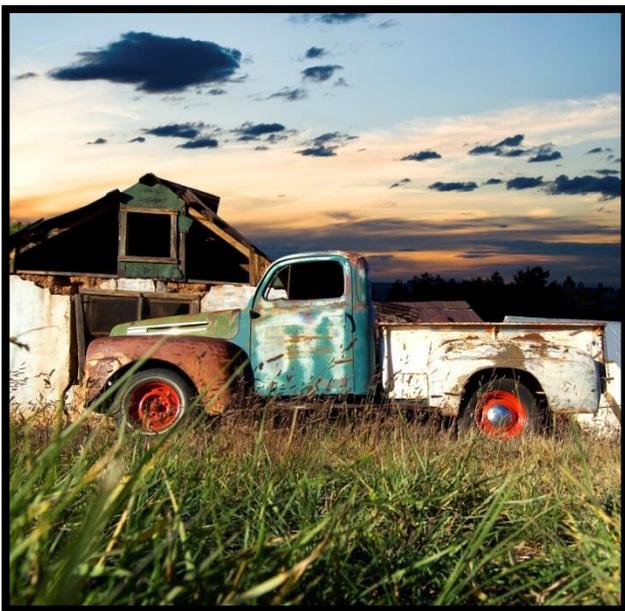
### *The impact of caregiving*

Family caregiving can negatively impact mental and physical health. Though conclusions of individual studies have varied regarding the effects of family caregiving, caregivers seem to have higher levels of stress and depression, and lower levels of subjective well-being and physical health, than non-caregivers. An analysis of 84 articles on health differences between caregivers and non-caregivers concluded that most of these differences were small to medium, except in dementia caregivers, who were at high risk for poor psychological and physical health.<sup>xix</sup> AARP's review of caregiver health research notes that, "Family caregivers face chronic health problems of their own and health risks, such as heart disease, hypertension, stroke, poorer immune function, slower wound healing, impaired self-care, sleep problems and fatigue, increased use of psychotropic drugs, and even death among highly stressed spouse caregivers."<sup>xx</sup>

New Mexico caregivers reported similar hardships. Among the state's current and former caregivers, two-thirds said they "felt stressed out emotionally" due to their caregiving responsibilities, 56 percent found it difficult to get enough rest, and 48 percent found it difficult to exercise regularly.

Financial strain is common as well. Participants in the caregiver forums voiced frustration that their financial positions were too strong to qualify for Medicaid benefits, but insufficient to support the care needs of their loved ones. Among current and former New Mexico caregivers, 60 percent reported having used their own money to help provide care, and 34 percent said they felt strained financially due to their caregiving responsibilities.<sup>xxi</sup>

Nationally, family caregivers of persons age 50 and older reported spending an annual average \$5,531 out-of-pocket in 2007. When the family caregiver is age 50 or older and has to leave the workforce to care for a parent, the economic toll is stunning. On average, a caregiver in this situation loses an estimated \$303,880 combined in wages, Social Security benefits, and pension benefits over a lifetime. The financial toll on women in this situation was even greater, an estimated average of \$324,044. According to AARP, "...assuming the role of caregiver for aging parents in midlife not only has a greater economic impact on female caregivers' retirement years but also may substantially increase women's risks of living in poverty and receiving public assistance in old age."<sup>xxii</sup>



### *Differences in rural and urban family caregivers*

A few differences emerged between urban and rural family caregivers in AARP New Mexico's family caregiving survey. Serving as a current caregiver was more prevalent among rural (22%) than urban respondents (18%). Urban and rural caregivers performed nearly all caregiving tasks with the same frequency, except bathing/dressing, which was done by 60 percent of rural caregivers, compared with 49 percent of urban caregivers.

Working was equally prevalent among rural and urban caregivers. Meanwhile, urban caregivers (70%) expressed feeling emotionally stressed more often than rural caregivers (60 %).<sup>xxiii</sup>

## Types of Caregiver Supports

### *Care coordination*

Caregivers often do not know where to turn for help. This was a consistent message from participants in the caregiver forums which informed this plan. Information about available community resources, an important aspect of care coordination, was identified by New Mexico caregivers as the most helpful type of caregiver support.<sup>xxiv</sup>



Though widely referred to and recognized for its importance in creating successful outcomes for caregivers and care recipients, the term “care coordination” is without a consensus definition.<sup>xxv</sup> The working definition for “care coordination” employed by the task force’s care coordination work group and used in this plan is the brokering of services by a professional who assists a caregiver in identifying, accessing and receiving services and supports to address needs without duplication of effort.

Care coordination services may focus on medical care or assist with community services and resources, long-term care planning, insurances, and other types of supports for the caregiver. People typically find themselves in the role of family caregiver without preparation, and successful care coordination can help ensure that a family caregiver is connected to appropriate available resources and information to meet his or her evolving needs.

ALTSD's Aging and Disability Resource Center (ADRC), available statewide via phone and online, serves as a single point of entry for New Mexicans and their caregivers seeking locally-available resources. The ADRC's Options Counselors utilize a series of questions to discern a client's needs, as well as potential eligibility for programs including Medicaid and Prescription Drug Assistance, and then connect the client with appropriate resources. These resources may include congregate and home-delivered meals, other types of nutrition assistance, adult day care, transportation, and in-home services. The ADRC has catalogued and continually verifies 4,000 resources available in New Mexico. These can also be

accessed directly online through the ADRC's searchable Social Services Resource Directory. The ADRC received more than 43,000 client contacts during state fiscal year 2014.

Many care coordination services are also provided by case managers and social workers. Often employed by health care systems and facilities, these professionals facilitate discharges into the community or from one facility to another, helping to ensure that supports are in place for successful transition. Such transition services are also publicly available through the ADRC's Care Transitions Bureau. Geriatric care managers, hired privately, also provide care coordination services.

New Mexico has recently emphasized the important role played by Community Health Workers (CHWs) in the delivery and planning of health services and health education, particularly in the state's rural and underserved communities. The Department of Health published a certification process for CHWs in May of 2015. Many CHWs can and do act as care coordinators, connecting families with appropriate resources available in their community. These professionals are well-positioned to identify and communicate local resource gaps, train family caregivers, and offer health promotion programs and education.



The task force's care coordination work group identified several barriers to accessing current care coordination systems. More optimum execution of care coordination in New Mexico is presently hampered by a lack of awareness of care coordination options, fragmentation of current service delivery systems, lack of funding for care coordination services, and lack of culturally- and linguistically-appropriate services.

To promote seamless transitions and resource connections, the work group recommended standardized training and technical assistance for professionals providing care coordination services. The work group also catalogued several evidence-based care coordination programs that have demonstrated levels of effectiveness in other states, including Benjamin Rose Institute Care Consultation, Support Health Activities Research Education, the Southern Illinois Rural Telehealth Project, Operation Family Caregiver, and the Dementia Care Family Caregivers Project.

During certain situations in the caregiving journey, such as hospitalizations and transitions from the hospital to home, rehab, or hospice services, care coordination services can be particularly helpful. The federal Administration for Community Living (ACL) has termed these “critical pathways,” times when people make important decisions about long-term care.<sup>xxvi</sup> Enacted in 2015, New Mexico’s Lay Caregiver Aftercare Designation Act addresses one type of critical pathway. This law requires that hospitals provide patients with an opportunity to designate a lay caregiver and that hospitals attempt to prepare designated caregivers for the provision of care that will be needed following patient discharge.

### *Training and planning*

The needs of care recipients, and family caregiver duties corresponding to these needs, change over time, increasing sharply with critical illness or injury and mounting steadily with age or incidence of chronic conditions. As previously noted, family caregivers are not usually prepared for these duties. Effective training of family



caregivers can serve to support the physical health of care recipients, as well as the psychological, emotional, and physical well-being of caregivers. In AARP New Mexico’s caregiving survey, 77 percent of respondents characterized having more resources and training for caregivers as either very or extremely important.<sup>xxvii</sup>

The Alzheimer's Association, New Mexico Chapter, has partnered with ALTSD to deliver the evidence-based Savvy Caregiver training for family caregivers of persons with dementia since 2008, but there appears to be need for a similarly effective training which is not disease specific. Several organizations, including some private home care agencies and the New Mexico Direct Caregivers Coalition, currently offer free training for family caregivers. Feedback received from New Mexico caregivers themselves, at caregiver forums and through surveys, indicated that many New Mexico caregivers remain untrained.

Advanced medical, financial and legal planning can also help to ease caregiver burden. Decisions made in advance by individuals allow them to exercise their rights to self-determination and also relieve family caregivers of having to make these difficult decisions. Ideally, advanced medical directives and powers of

attorney should be completed before crises arise. No-cost assistance with such planning is available to older adults through the Legal Resources for the Elderly program, a statewide project of the New Mexico Bar Foundation, as well as the Albuquerque-based Senior Citizens Law Office. The task force recommended public awareness efforts aimed at increasing advanced planning.

The online AARP Caregiver Resource Center, [www.aarp.org/caregiving](http://www.aarp.org/caregiving), provides information and tools for preparing for and providing caregiving. AARP's state office also offers "Prepare to Care," a published planning guide to help individuals and families.

Caregiver burden is inversely related to the independence of the care recipient. Generally, the more tasks the care recipient is able to complete without assistance the fewer tasks that must be addressed by the caregiver. To this end, the task force recommended supporting healthy aging efforts. Such current efforts targeting older New Mexicans include the evidence-based fitness program EnhanceFitness®, New Mexico Senior Olympics, and Manage Your Chronic Disease, an evidence-based disease self-management program offered through collaboration between the Department of Health and ALTSD.



With the time demands created by caregiving, training and planning resources must be offered in a manner convenient to family caregivers. To encourage access by caregivers statewide, training and planning resources should be available both in person and online.

## *Additional resources and supports*

Family caregivers need respite, information, and support. As noted in *The International Journal of Aging and Human Development*, “Respite, or having time away from providing direct care to a person needing care, has been identified as one of the most desired and needed forms of assistance for family caregivers.”<sup>xxviii</sup> Seventy-three percent of current or former New Mexico caregivers characterized respite as very helpful (57%) or somewhat helpful (25%).<sup>xxix</sup>



New Mexico’s aging network providers, which include local senior service providers throughout the state, delivered 379,097 hours of respite care in 2014, a statistic which included adult day care and respite reimbursement. A host of private duty home care agencies also fill family caregivers’ respite needs, but are beyond the financial means of many families and subsidies are limited. The Senior Companion Program pairs senior volunteers with frail elders, providing respite for family caregivers.

Family caregivers’ access to respite may be stymied by lack of availability, affordability, and information regarding respite options and the importance of utilizing respite. The task force’s family support work group identified a need to expand respite resources in New Mexico. To address this need, the work group recommended increasing the student and volunteer workforce available to give family caregivers a break.

Families commonly struggle to collaborate in the provision of care to loved ones. *The Savvy Caregiver* program curriculum identifies five different types of caregiving situations. These range from solitary caregiving without any assistance, to tag team caregiving in which primary caregiver responsibility periodically shifts from one person to another, to collaborative caregiving in which different people address different caregiving needs.<sup>xxx</sup>

The family support work group identified several means of better organizing care and activating family and social circles in care delivery. One such option is “Lotsa Helping Hands,” a social media website which allows caregivers to calendar a care recipient’s needs and invite family and friends to donate time to meet those needs.

New Mexico's aging network providers offer a host of other resources for older adults, including congregate and home-delivered meals, transportation,

homemakers, home repair, and chore services. Though often thought of as assisting the service recipient, these resources also provide relief for the service recipient's family caregiver. Each meal, trip to the grocery store, or home chore furnished to a care recipient by an aging network provider removes that task from a family caregiver's to-do list. During state fiscal year 2014, nearly 51,000 older New Mexicans received 3.7 million meals from aging network providers. These providers also accounted for more than 693,000 trips to seniors with transportation needs.



A study published in *The Gerontologist*<sup>xxxi</sup> suggested that caregivers can enjoy good quality of life, even if their caregiving burdens increase, if they have social support systems in place and feel supported. Support groups connected to specific conditions, such as cancer, autism, or dementia, are available for family caregivers in many communities, but the family support work group noted a need for more general support groups for family caregivers of elders, as well as conferences and outings that would draw caregivers together. Support communities are also available online or can be supported by phone trees.

Employers should also be encouraged to support employees who are family caregivers. Costs to replace a worker are high and retention of workers would carry with it the benefit of high loyalty and morale among

retained workers. Employers should be educated as to these realities, as well as to the negative impacts of discriminating based on family caregiver responsibilities.

Employers should also be recognized for their efforts to support family caregivers.

To benefit from available resources, New Mexico's family caregivers need information. Instructions for organizing care using family and friends, getting the most out of respite, participating in support groups and activities, and accessing training and planning tools can be paired with care coordination to ensure that New Mexico's family caregivers maximize their own abilities and receive needed assistance.

## Goals and Strategies

To address the challenges facing New Mexico's family caregivers, the following goals are recommended, along with strategies for accomplishing described goals.

These strategies should be implemented so as to effectively respect and incorporate ethnic and cultural traditions, and address the rural and frontier nature of the state, as well as its high rate of poverty.

Realization of these goals will require the coordinated efforts of the manifold public agencies and private organizations that touch family caregivers, and of family caregivers themselves.





Goal One: *Ensure that family caregivers access the resources they need*

1. Create the Caregiver Resource Center within the Aging and Disability Resource Center. The Caregiver Resource Center will connect family caregivers with resources, training, support, respite, and planning tools. In service of this function, the Caregiver Resource Center will feature an easily-searchable website, organized around family caregiver needs, which houses or connects family caregivers to relevant online resources, training, support, and planning tools.
2. Have ALTSD assume responsibility for overseeing plan implementation. The Department should continue convening partners to:
  - a. Identify current resources and enhance communication and collaboration between these resources in a manner which maximizes efforts toward achievement of the goals of The New Mexico State Plan for Family Caregivers;
  - b. Establish a timeline for implementation of strategies to further goals, as well as appropriate metrics to measure success of strategies; and
  - c. At least annually, review progress toward achieving the goals of the State Plan.
3. Increase referrals by all likely points of contact to appropriate resources by utilizing existing entities to create a no-wrong-door system, increasing inter-programmatic access and referral through all available mediums family caregivers are likely to access, including websites, helplines, and face-to-face contacts. Particularly, medical personnel and those who support them must be adept at referring family caregivers to appropriate resources.
4. Conduct public awareness campaigns to:
  - a. Help family caregivers to self-identify;
  - b. Make family caregivers aware of available resources, particularly those

adept at leading family caregivers to other resources to meet caregivers' individual needs; and

- c. Alleviate family caregivers' psychological barriers, such as guilt and the desire to be the only person providing direct care, that impede caregiver self-care and access to resources, training, support, and respite.

5. Assess family caregiver needs using online and printed self- and family-assessment tools. Connect family caregivers with points of contact for appropriate resources based on such assessments.
6. Use current available research to determine the types of information most requested by family caregivers and how this is best received and used by family caregivers.
7. Develop and/or disseminate presentations and materials needed to connect family caregivers with appropriate resources.



## Goal Two: *Ensure that family caregivers are properly trained*

1. Inventory and support training programs for family caregivers, particularly those that are evidence-based or have been tested and demonstrated to be effective. Ensure that information, including schedules, for such programs is aggregated and made easily accessible to family caregivers.
2. Ensure that training is available and easily accessible both in person and online to meet the variety of family caregiver training needs, including, but not limited to:
  - a. Caregiver basics
  - b. Managing care of others
  - c. Financial caregiving
  - d. Legal issues
  - e. Medical/mental health support
  - f. Communication with family members, care recipients, and medical professionals
  - g. Physical tasks of caregiving
  - h. Caregiver self-care
  - i. End-of-life issues
3. Broaden availability of training for family caregivers using culturally relevant train-the-trainer training for community trainers, including Community Health Workers.
4. Support deployment of programs for youth who are caregivers for parents or grandparents.
5. Explore delivery of in-person training in settings which allow multiple family caregiver needs, such as support, respite, and resource connection, to be met concurrently.
6. Broaden the points of referral for connecting family caregivers with training, including Community Health Workers and state-funded home and community based services as feasible.



### Goal Three: *Limit future caregiver burden*

1. Increase elder independence and reduce caregiver burden through support of healthy aging initiatives and related community resources.
2. Increase advanced financial, legal, and medical planning by the public at large to reduce caregiver burden.



#### Goal Four: *Ensure that family caregivers are supported*

1. Equip family caregivers to develop communities of support, with online, printed, and in-person instruction. Examples of such communities of support include:
  - a. Telephone trees
  - b. On-line support/chat
  - c. Church groups
  - d. Warm lines for telephone support
  - e. Traditional support groups
2. Foster development of in-person and online support groups for caregivers of older family members who are declining not due to a single, specific disease.
3. Create additional opportunities for family caregiver peer support. Examples include:
  - a. Training events, which also encourage family caregivers to share their stories; and
  - b. Outings which encourage both family caregiver and care recipient to participate together.
4. Target public awareness to increase participation in caregiving beyond the primary caregiver and to enhance understanding of family caregiving issues by the public at large. To this end, family caregivers should be encouraged and empowered to publicly share their stories.
5. Advocate as appropriate on behalf of family caregivers with relevant public agencies and private organizations.
6. Disseminate information in person, online and through printed materials to assist family caregivers in preparing for the end of caregiving, including final arrangements and grief support.



*Goal Five: Make family caregiving easier through coordination of care*

1. Create a matrix of current care coordination systems to determine locations, eligibilities, costs, duplications, and identification of barriers and gaps. Develop strategies to link these systems.
2. Support the development of an umbrella care coordination system for family caregivers, in which the Caregiver Resource Center is a central point of referral.
3. Encourage and promote the use and development of care coordination programs that are evidence-based or have been tested and demonstrated to be effective. These programs should be adapted as appropriate to meet the rural and cultural needs of New Mexico caregivers.
4. Encourage and promote coordinated training, credentialing, and continuing educational events for current care coordination staff.
5. Promote and encourage care transitions planning and support from hospital to home, rehab, and hospice.
6. Promote the use of caregiver assessments in care coordination systems.
7. Encourage inclusion of curriculum that will increase knowledge of family caregiver needs and available resources in appropriate courses of study in New Mexico community colleges, universities, and the Community Health Worker certification program.
8. Encourage hospitals to identify a family caregiver to receive appropriate training before discharge to home.

9. Promote and encourage the implementation of programs and systems to better meet the needs of family caregivers.
10. Examine means of supporting financial relief for family caregivers.



Goal Six: *Ensure support for family caregivers who work*

1. Educate employers about the special needs of caregivers and the importance of retaining employees who are engaged in family caregiving.
2. Develop an annual award to provide recognition to the most "family friendly" employer(s) that focuses on eldercare responsibilities.
3. Educate caregivers and employers about family caregiving responsibility, discrimination, and strategies for reducing the risk of legal action.



Goal Seven: *Ensure that family caregivers access respite*

1. Create a directory of local respite care, available to family caregivers. This directory should be easily navigated and available online, in print, or via phone.
2. Assist family caregivers in organizing the care of their loved ones. This assistance should be available online and in person, and should include a system for identifying necessary caregiving tasks and enlisting the assistance of people beyond the primary caregiver in completing these tasks.
3. Explore strategies to increase respite options for family caregivers, including enlisting students and volunteers in providing respite to family caregivers.
4. Increase family caregiver awareness regarding available respite options and the benefits of respite.

## Conclusion

The challenges posed by family caregiving in New Mexico are large and growing. This plan proposes to address these challenges through well-coordinated support, training, planning, and preventive measures.

Successful implementation of this plan promises to maximize the abilities of family caregivers while providing them with needed assistance. Such implementation will require the concerted efforts of state and local government, private organizations, providers, communities, and families. The Aging and Long-Term Services Department will be a convener for these stakeholders to achieve the goals set forth in this plan. Together, these entities can make New Mexico a place where providing care for a loved one is easier, and family caregivers and their loved ones enjoy better quality of life.



## Members and Participants

### Adrienne R. Smith

*President and CEO, New Mexico Direct Caregivers Coalition*

### Agnes Vallejos

*Former Executive Director, Alzheimer's Association, New Mexico Chapter*

### Amylee Udell

*New Mexico Direct Caregivers Coalition*

### Annette M. Lopez

*Manager, Care Coordination, United Healthcare Community Plan of New Mexico*

### Beth Velasquez

*Associate Director for Communications, AARP New Mexico*

### Bev Dow

*Family Caregiver*

### Capt. Walt Baker

*Volunteer, AARP New Mexico*

### Cathy Roche

*Deputy Director, Public Health Division, New Mexico Department of Health*

### Carlos Moya

*Director, Consumer and Elder Rights Division Director, Aging and Long-Term Services Department*

### Chris Di Gregorio

*Volunteer, AARP New Mexico*

### Connie Sedillo

*Supervisor, Bernalillo County Area Agency on Aging, City of Albuquerque*

### Danny Placencio

*Deputy Director, Department of Family and Community Services, City of Albuquerque*

### Denise Wilcox

*Manager, Human Resources, New Mexico Gas Company*

### Devon Neale

*Assistant Professor, Department of Internal Medicine, University of New Mexico*

**Donna L. Wagner**

*Dean, College of Health and Social Services, New Mexico State University*

**DuWayne Branscombe**

*Family Caregiver*

**Elaine Ryan**

*Vice President of State Advocacy and Strategy Integration, AARP New Mexico*

**Elsa Baker**

*Executive Council, AARP New Mexico*

**Emily Freede**

*Gerontologist, A.G.E.*

**Fred Schaum**

*Former Director, Policy and Planning, Aging and Long-Term Services Department*

**Gary Giron**

*Executive Director, Alzheimer's Association, New Mexico Chapter*

**Gene Varela**

*State Director, AARP New Mexico*

**Gina Gallardo**

*Bureau Chief, Consumer and Elder Rights Care Transition, Aging and Long-Term Services Department*

**Gino Rinaldi**

*Former Cabinet Secretary, Aging and Long-Term Services Department*

**Jackie Cooper**

*State President, AARP New Mexico*

**Jamie Frye**

*Former Director of Communications and Advocacy, Alzheimer's Association, New Mexico Chapter*

**Janis Hazle**

*AARP New Mexico*

**Janis McGlone, LMSW**

*Agency Director, Retreat at Home*

**Jaretta Faust**

*Executive Council, AARP New Mexico*

**Jennie DiGregorio**

*Executive Council, AARP New Mexico*

**Jeremiah Kelly, MD, MMM**

*Geriatrician*

**Jim Dolbier**

*Regional Volunteer Director, AARP New Mexico*

**Joan McIver Gibson**

*Consulting Ethicist*

**Joie Glenn**

*Executive Director, New Mexico Association for Home and Hospice Care*

**Jon Weiss**

*Volunteer, Alzheimer's Association, New Mexico Chapter*

**Joy Cayaditto**

*Executive Council, AARP New Mexico*

**Karen Peterson**

*Director, Governor's Commission on Disability*

**Larry Kronen**

*Senior Staff Attorney, Pegasus Legal Services for Children*

**Leonel Garza**

*Executive Council, AARP New Mexico*

**Lisa Storti**

*Manager, Developmental Disabilities Support Division, Department of Health*

**Liz McGrath**

*Executive Director, Pegasus Legal Services for Children*

**Lora Church, M.P.A., M.S.**

*Director, Indian Area Agency on Aging, Aging and Long-Term Services Department*

**Lynne Anker-Unnever**

*Director, Aging Network Division, Aging and Long-Term Services Department*

**Margy Wienbar**

*Executive Director, HealthInsight New Mexico*

**Maria Zamora-Hughes**

*Former Executive Director, InnovAge Greater New Mexico PACE*

**Martin Rosenblatt**

*Regional Executive Director, InnovAge Greater New Mexico PACE*

**Mary Ann Kreski**

*Caregiver Support Coordinator, New Mexico Veteran's Administration Health Care System*

**Mary Stockley**

*Executive Council, AARP New Mexico*

**Michaela Valencia**

*Family Caregiver*

**Michelle Briscoe**

*Manager, Bernalillo County Area Agency on Aging, City of Albuquerque*

**Michael Donnelly**

*Associate State Director, Advocacy, AARP New Mexico*

**Myles Copeland**

*Secretary-designate, Aging and Long-Term Services Department*

**Nicole Taylor**

*Lovelace Respiratory Research Institute*

**Orlando Vasquez**

*Medical Assistance Division, Human Services Department*

**Patricia M. Gallegos, LMSW**

*Community Services Manager, Office of Community Health Worker, Department of Health*

**Roberta Gonzales, LISW**

*Caregiver Support Coordinator, New Mexico Veteran's Administration Health Care System*

**Roxroy Reid**

*University of New Mexico*

**Sheryl Inglat**

*Gerontologist/Owner, Comfort Keepers*

**Siobhan Hancock, MSG**

*CSFP-FMNPs Program Manager, Department of Health*

**Susan Reinhard**

*AARP New Mexico Public Policy Institute*

**Susan Stuart**

*Owner/Care Manager, Decisions in Care*

**Tim Hale**

*Former Secretary, Department of Veterans Services*

**Tracy Wohl**

*Director, Office of Alzheimer's and Dementia Care, Aging and Long-Term Services Department*

**Vangie Chavez**

*Program Coordinator, Office of Alzheimer's and Dementia Care, Aging and Long-Term Services Department*

## References

- <sup>i</sup> *Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009*. AARP Public Policy Institute. June, 2011.
- <sup>ii</sup> *Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009*.
- <sup>iii</sup> *Caregiving in the U.S. 2009*. National Alliance for Caregiving and AARP, November, 2009.
- <sup>iv</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*. AARP Research. 2014
- <sup>v</sup> U.S.Census Bureau, Population Division, Interim State Population Projections, 2005. Web. June 5, 2015.  
[http://www.aoa.acl.gov/Aging\\_Statistics/future\\_growth/DOCS/Interim\\_State\\_Projections\\_of\\_Pop\\_for\\_5Yr\\_Age\\_Groups\\_07012004to2030.xls](http://www.aoa.acl.gov/Aging_Statistics/future_growth/DOCS/Interim_State_Projections_of_Pop_for_5Yr_Age_Groups_07012004to2030.xls).
- <sup>vi</sup> *Family Caregiving: The Facts*, Centers for Disease Control and Prevention. Web. June 19, 2015.  
<http://www.cdc.gov/aging/caregiving/facts.htm>.
- <sup>vii</sup> Redfoot, Donald, Lynn Feinberg and Ari Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers*, AARP Public Policy Institute, Aug., 2013.
- <sup>viii</sup> *2015 Report: Caregiving in the U.S.*, AARP Public Policy Institute and National Alliance for Caregiving, June, 2015. Web. June 24, 2015. [http://www.caregiving.org/wp-content/uploads/2015/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf).
- <sup>ix</sup> Garrett, M.D., & McGuire, L.C. (2008). American Indian/Alaska Native Communities Face Aging with Fewer Caregivers. *Aging Today*, 29(6), 11.
- <sup>x</sup> IOM, 2008
- <sup>xi</sup> Goins, 2008: Goins, R. "Results from the National Tribal Long-Term Care Study," December 2008.
- <sup>xii</sup> <http://www.cdc.gov/aging/caregiving/activities.htm>
- <sup>xiii</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xiv</sup> Reinhard, Susan C., Carol Levine and Sarah Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care*, AARP, June, 2012.
- <sup>xv</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xvi</sup> *Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009*.
- <sup>xvii</sup> Feinberg, Lynn and Rita Choula, *Understanding the Impact of Family Caregiving on Work*, AARP Public Policy Institute, October, 2012.
- <sup>xviii</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xix</sup> Pinquart, Martin; Sörensen, Sylvia. "Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis." *Psychology and Aging*. 2003, Vol. 18, No. 2, 250-267. Web. June 5, 2015.  
[http://www.researchgate.net/publication/10691251\\_Differences\\_between\\_caregivers\\_and\\_noncaregivers\\_in\\_psychological\\_health\\_and\\_physical\\_health\\_a\\_meta-analysis](http://www.researchgate.net/publication/10691251_Differences_between_caregivers_and_noncaregivers_in_psychological_health_and_physical_health_a_meta-analysis).
- <sup>xx</sup> *Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009*.
- <sup>xxi</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xxii</sup> *Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009*.
- <sup>xxiii</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xxiv</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xxv</sup> *Chapter 2. What is Care Coordination?: Care Coordination Measures Atlas Update*. Rockville, MD: Agency for Healthcare Research and Quality, June 2014. Web. June 19, 2015. <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html>.
- <sup>xxvi</sup> Administration for Community Living. Web. June 19, 2015.  
<http://www.acl.gov/Programs/CDAP/OIP/EvidenceBasedCare/index.aspx>.
- <sup>xxvii</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*. AARP Research. 2014
- <sup>xxviii</sup> Lund, Dale A., et al, "Time for Living and Caring: An Intervention to Make Respite More Effective for Caregivers," *The International Journal of Aging and Human Development*, Vol. 79(2); 2014.
- <sup>xxix</sup> *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.
- <sup>xxx</sup> Hepburn, K., et al, *The Savvy Caregiver*, University of Minnesota, 2008.
- <sup>xxxi</sup> Chappell, Neena L. and R. Colin Reid, "Burden and Well-Being Among Caregivers: Examining the Distinction," *The Gerontologist*, Vol. 42, No. 6, 772-780, December, 2002.

# Information and Resources

---

## State of New Mexico

### Aging and Long-Term Services Department

2550 Cerrillos Road

PO Box 27118

Santa Fe, New Mexico 87502-7118

505-476-4799

Statewide toll-free: 866-451-2901

### Aging and Disability Resource Center

2550 Cerrillos Road

PO Box 27118

Santa Fe, New Mexico 87502-7118

505-476-4846

Statewide toll-free: 800-432-2080

TTY: 505-476-4937

