

New Mexico State Plan for Family Caregivers

Legislative Health & Human Services Committee

Sept. 22, 2015

Myles Copeland, Cabinet Secretary Designate

Aging & Long Term Services Department

505-476-4708 myles.copeland@state.nm.us

Gene Varela, State Director

AARP

505-946-3604 evarela@aarp.org



Agenda

- Background
- Process
- Challenges
- Supports
- Goals & Strategies

Scope of Family Caregiving

- **419,000 New Mexicans serve as family caregivers annually**
 - 287,000 at any time
 - Avg. 18.4 hours unpaid care weekly (274 million/year)
 - Contribute \$3.1 billion in unpaid care
- **Nationally, family caregivers:**
 - Provide 80% of long-term care
 - Contribute \$306 billion annually



Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009. AARP Public Policy Institute. June, 2011. *Caregiving in the U.S. 2009.* National Alliance for Caregiving and AARP, November, 2009.

Planning Process

Family Caregiver Task Force convened, April, 2014

- Pursuant to House Joint Memorial 4 (2014)
 - Rep. Tomas Salazar, AARP, ALTSD
 - Focused on family caregivers of elders
 - Named 20 public and private organizations and stakeholder groups
 - Report to LHHS by November 2015

Planning Process

50+ participants, including:

- Family caregivers
- AARP
- Alzheimer's Association
- NM Direct Caregivers Coalition
- Dept. of Health
- United Healthcare
- Indian Area Agency on Aging
- NM Gas Co.
- UNM
- NMSU
- Dept. of Veterans Services
- NM Assoc. for Home Care & Hospice
- Governor's Commission on Disabilities
- Pegasus Legal Services
- Human Services Dept.
- Health Insight NM
- Innovage PACE
- NM VA Health Care System
- Lovelace Respiratory Institute
- Private home care agencies



Planning Process

Public feedback from 600+

- 3 caregiver forums
- 4 ALTSD listening sessions
- Online surveys

AARP telephone survey on family caregiving

- 1,000 registered voters 45+
- Oversampled rural counties
- Follow-up calls to non-English speaking households



Planning Process

Adopted 4 overarching principles:

- 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

Planning Process

5 Work Groups:

- Family support
- Training and planning
- Care coordination
- Support for working caregivers
- Public awareness

Identified:

- Family caregivers' needs
- Current resources for addressing needs
- Gaps between needs and current resources
- Recommendations for addressing such gaps

Planning Process

Intent of plan

- 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.

Challenges: Growth

- **Average age of NM care recipients is 80**
- **New Mexico's 80+ population will increase 80.5% by 2030**
- **Caregiver ratio = potential caregivers ages of 45-64 for each person aged 80**
 - 7 to 1 in 2010 **(nationally)**
 - 4 to 1 in 2030
 - 3 to 1 in 2050



Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+. AARP Research. 2014 U.S. Census Bureau, Population Division, Interim State Population Projections, 2005. Web. June 5, 2015. 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.

Challenges: Demographics

- **60% of family caregivers are women.**
- **Higher percentage of Hispanics than Non-Hispanic Whites serve as family caregivers.**
- **Number of Native Americans aged 75+ will double in the next 25 years.**
 - Caregiver ratio will be further reduced by out-migration from reservations.



Challenges: Caregiving Tasks

➤ NM family caregivers said they had done the following tasks for their loved one:

- Shopping (92%)
- Transportation (90%)
- Chores (88%)
- Meals (87%)
- Medication management (74%)
- Financial management (69%)
- Medical tasks (71%)
- Assistance with bathing or dressing (53%)

➤ 1/3 of caregivers have more than 1 care recipient **(nationally)**



Challenges: Working Caregivers

- **74% of adults with eldercare responsibilities have worked while caregiving (nationally)**
- **Among New Mexico's working caregivers:**
 - 69% altered their work schedule or took time off
 - 34% took a leave of absence
 - 24% went from working full-time to part-time



Feinberg, Lynn and Rita Choula, *Understanding the Impact of Family Caregiving on Work*, AARP Public Policy Institute, October, 2012. *Caregiving in New Mexico: A Survey of New Mexico Registered Voters Age 45+*.

Challenges: Impact of Caregiving

➤ **Caregivers have:**

- Higher stress & depression
- Lower subjective well-being & physical health
 - Differences are small to medium, except for in dementia caregivers

➤ **Caregiver health risks include:**

- Heart disease
- Hypertension
- Stroke

Challenges: Impact of Caregiving

- **New Mexico caregivers reported:**
 - Feeling stressed out emotionally **(66%)**
 - Difficulty getting enough rest **(56%)**
 - Difficulty exercising regularly **(48%)**

Challenges: Financial

- **New Mexico caregivers reported:**
 - Having to use their own \$ to provide care **(60%)**
 - Feeling financially strained due to caregiving **(34%)**
- **Frustration with Medicaid/private pay gap**
- **Nationally, family caregivers 50+ spend \$5,531 avg./year out of pocket**
 - Those who leave workforce to care for a parent lose \$303,880 **(wages/social security/pension)**
 - \$324,044 among women



Supports: Care coordination

- **Info about community resources was rated by NM Caregivers as the most helpful type of support.**
- **Resources:**
 - Aging and Disability Resource Center
 - Assess needs
 - Eligibility (Medicaid/Prescription Drug Assistance)
 - 4,000+ resources
 - 43,000 client contacts (FY14)
 - Care Transitions Bureau
 - Case managers
 - Social workers
 - Geriatric care managers



Supports: Training and Planning

- **Caregiver burden is inversely related to independence of the care recipient**
- **Healthy aging programs help to maintain independence:**
 - EnhanceFitness®
 - NM Senior Olympics
 - Manage Your Chronic Disease
- **Advanced medical, financial and legal training**
 - Allow for self-determination
 - Ease caregiver burden
 - Resources include:
 - LREP (statewide)
 - SCLO (Albuquerque)

Supports: Training and Planning

- **77% of NM family caregivers say more resources and training for caregivers is very or extremely important.**
- **Caregiver training offered by:**
 - Alzheimer's Association
 - NM Direct Caregiver's Coalition
 - Private home care agencies
- **Planning and training resources should be available online:**
 - aarp.org
 - caregiveraction.org

Supports: Respite

- **73% of NM caregivers characterized respite as very or somewhat helpful**
- **Resource include:**
 - NM Aging Network (379,097 hours in FY14)
 - Private duty home care agencies
 - Senior Companions volunteers
- **Organizing care/activating family and friends:**
 - Lotsa Helping Hands

Additional Supports

- **Senior service providers**
 - Meals (3.7 million to 51,000 seniors in FY14)
 - Transportation (693,000 trips in FY14)
- **Senior support groups**
 - Non-disease specific groups are needed
 - Should be available in-person, on-line or via phone
- **Employers**

Goals & Strategies

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

1. Create the Caregiver Resource Center within the Aging and Disability Resource Center.
2. Have ALTSD assume responsibility for overseeing plan implementation.
3. Increase referrals to appropriate resources.
4. Conduct public awareness campaigns.
5. Assess family caregiver needs.
6. Use available research to determine the types of information needed.
7. Disseminate presentations and materials.



Goals & Strategies

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

1. Inventory and support training programs.
2. Ensure that training is available and easily accessible.
3. Broaden availability of training through community groups, youth programs, in-person training opportunities with support services.
4. Broaden points of referral for connecting family caregivers with training.

Goals & Strategies

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.

Goals & Strategies

Goal Four: *Ensure that family caregivers are supported*

1. Equip family caregivers to develop communities of support, with online, printed, and in-person instruction.
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.
4. Target public awareness to increase participation in caregiving.
5. Advocate on behalf of family caregivers.
6. Disseminate information to prepare for the end of caregiving.

Goals & Strategies

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.
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.
4. Encourage and promote training and credentialing of care coordinators.
5. Promote and encourage care transition planning and support.
6. Promote the use of caregiver assessments in care coordination systems.
7. Encourage inclusion of curriculum about caregiving in colleges, universities and other training programs.
8. Encourage hospitals to identify family caregivers and provide appropriate training before discharge. (**Lay Caregiver After Care Training Act – HB139**)
9. Promote and encourage the implementation of programs and systems to better meet the needs of family caregivers.
10. Examine means of providing financial relief for family caregivers.



Goals & Strategies

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.

Goals & Strategies

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.

