

## Program and Policy Considerations for Supporting Caregivers

### KEY FINDINGS

Through interviews with state agencies and community-based organizations, ASTHO identified how components of public health support caregiving initiatives with the following recommendations.

- Convene statewide partnerships with diverse representation
- Strengthen the caregiving workforce's capacity
- Identify models of sustainability

### Background

The current growth in the number and proportion of older adults in the United States is unprecedented in our history. The rapidly aging population is driven by two realities: longer lifespans and aging baby boomers, which combined will double the population of older Americans over the next 25 years.<sup>1</sup>

Currently, older adults are displaying a strong preference for “aging in place,” defined as the

ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level.<sup>2</sup> This social shift is leading to an increasing number of naturally occurring retirement communities emerging within states. A recent AARP survey indicated that 85 percent of baby boomers plan on staying in current homes as they age.<sup>3</sup>

This societal shift is further seen in the increasing number of people reporting that they devote time and energy to caregiving. Families, more than social service agencies, nursing homes, or government programs, are the primary providers of long-term care for older adults in the United States. More than 44 million individuals are considered informal caregivers, providing unpaid help to those who live in the community and have at least one limitation in their activities of daily living.<sup>4</sup> These caregivers include spouses, adult children, and other relatives and friends. The typical family caregiver is a woman fifty years of age or older caring for an elderly parent or relative who does not live with her. This woman is likely married and employed.<sup>5</sup> According to the Institute of Medicine, 80 percent of care partners are family members in home settings. The average length of time caregivers report providing care is 4.6 years; in the case of dementia, caregiving may range from four to 20 years.<sup>6</sup> In 2013, an estimated five million Americans aged 65 and older had Alzheimer's disease.<sup>6</sup>

The contributions of caregivers remain largely unrecognized in discussions of financing and costs of healthcare and long-term services and supports, while their efforts are a critical extension of our formal healthcare system. In 2012, 15 million Americans provided 17.5 billion unpaid hours of caregiving with an economic value estimated at \$216 billion.<sup>7</sup> In an AARP survey, half of caregivers reported direct out-of-pocket expenditures averaging \$200 per month. Caregivers experience other significant indirect economic losses, such as loss of income security and employment benefits, as well as changes in their working patterns. Care providers face the loss of income through reduction in work hours or voluntary termination, leading to shrinking employer-based medical and retirement benefits. Caregiving also builds vulnerability to physical health risks, emotional strain, and mental health problems, such as depression, as well as social isolation.<sup>8</sup>

## National Policies

Acknowledging and supporting families and friends who provide care is a critical component of a comprehensive long-term-care system. The economic impact associated with being a caregiver continues to be a challenge, and the support provided by these individuals is irreplaceable. The formal caregiving workforce lacks strength in numbers, and as the number of those needing care increases, it is essential to support family caregivers as partners in care, not resources to be used until exhausted.<sup>9</sup> Their mental and physical health and well-being are causes for concern among public health and primary care professionals.

The United States healthcare system is oriented toward the patient, not the family caregiver, and therefore the patient is the party legally entitled to receive services.<sup>9</sup> Policymakers' responsibility is to balance individual needs and community resources. Several federal, state, and private programs offer financial and other assistance to family caregivers. The timeline on the right provides more information on specific legislation and programs.<sup>10</sup>

Promising steps have been taken in the past few years to recognize family caregivers as partners to formal service providers, particularly within the Patient Protection and Affordable Care Act (ACA).<sup>11</sup> ACA underscores the importance of care coordination as a means of removing barriers to accessing care, among other significant strides forward advocating for training and support.

The National Alzheimer's Project Act convenes a diverse set of stakeholders into three subcommittees on an Advisory Council on Alzheimer's Research, Care, and Services: research, clinical care, and long-term services and supports. The advisory council releases recommendations annually.<sup>12</sup>

### Medicare's Hospice Benefit

- Made permanent by Congress in 1986
- Addresses the patient's and family's needs
  - o "Unit of care" is the family, not just the patient

1986

### Family and Medical Leave Act

- Guarantees up to 12 weeks of job-protected *unpaid* leave for worker's own health needs or for certain family care (child, spouse, parent)

1993

### Older Americans Act, National Family Caregiver Support Program

- Caregiver as client—culture change in the aging network
- Provides caregiver support services (i.e., family counseling, support groups, training, respite care)
- Funding level: \$155 million

2000

### Lifespan Respite Act

- Expands and enhances respite services in states
- Funding level: \$2.5 million

2006

### Patient Protection and Affordable Care Act

- Promotes new models of care to improve care transitions, coordinate care, and test concurrent care for Medicare beneficiaries

2010

### National Alzheimer's Project Act

- Creation of national strategic plan and coordination of Alzheimer's disease efforts across the federal government

2011

## State Case Studies

*Much of the progress made in family caregiving has taken place through state governments and community-based organizations that provide information, referrals, and in-home support, as well as caregiver assessment, counseling, and respite services. In February and March 2014, ASTHO conducted seven hour-long interviews with state agencies and community-based organizations to reveal how components of public health support caregiving in tandem with other components and sectors.*

### California

The Alzheimer's Association California Southland Chapter partnered with state agencies, community service providers, and program consumers to implement the **Dementia Care Network Model**. The networks were developed in response to the need for community-based, long-term-care services resulting from an increase in the number of ethnically diverse dementia-affected individuals. The model partners trusted community agencies that have deep understandings of cultural norms where network members can share knowledge and build on each other's strengths to develop a culturally accepted set of support services for people with dementia and their families. To date, the model continues to demonstrate how the practical application of community organization strategies, training and technical assistance, and funding can improve access, service, and consumer satisfaction among underserved ethnic groups. In the model's latest iteration, focusing on Asian/Pacific Islander communities in Los Angeles, a six-month post-test assessment completed by 89 caregivers revealed a statistically significant increase in the use of case management, information and referrals, caregiver support groups and training programs, and transportation and legal services for care recipients. The post-test results also indicated a statistically significant decrease in levels of depression among caregivers.

### Georgia

The Atlanta Regional Commission, in collaboration with the Rosalynn Carter Institute for Caregiving and the Georgia Department of Human Services, uniquely serves persons with Alzheimer's and other dementias and their caregivers through **Benjamin Rose Institute (BRI) Care Consultation**, a telephonic evidence-based intervention. BRI Care Consultation empowers family caregivers and care receivers by providing information about health problems and available resources. This mobilizes and facilitates the use of informal supports and formal services and provides emotional support. Among three Georgia area agencies on aging (AAAs)—Atlanta Regional Commission (urban), Legacy Link AAA (urban and rural), and Heart of Georgia AAA (very rural)—BRI Care Consultation has served 625 caregivers in 40 Georgia counties over 2.5 years. From 2011 to 2013, 12 months post enrollment there have been significant increases in meeting caregiver needs in managing daily care tasks, accessing services, and emotional support, among others.

### Maine

The Maine Department of Health and Human Services Office of Aging and Disability Services collaborates with statewide interdisciplinary partners to deliver the evidence-based **Savvy Caregiver Program**. The program, offered as a two-part series, was expanded in Maine in 2013 to reach caregivers of individuals with intellectual and developmental disabilities and dementia. Savvy Caregiver is an evidence-based psycho-education curriculum for caregivers of those living with dementia in the community designed to support adjustments in approach and environment. Outcomes of Savvy Caregiver indicate that more than 1,500 participating caregivers have improved self-efficacy in their ability to respond to disruptive behavior and have experienced a reduction in depressive symptoms and

negative reactions to the care recipient's behavior. These outcomes were sustained at 12 months. Since August 2011, 184 caregivers have been reached through Part II, and outcomes suggest improved competence in skills as the disease moves into later and more challenging stages, reduced symptoms of depression, and improved mood.

## North Carolina

The North Carolina Division of Aging and Adult Services provides family consultation and support services to family members who are caring at home for a relative with dementia through **Project C.A.R.E.** Strong partnerships among the AAAs, Duke Family Support Program, Alzheimer's North Carolina, and local departments of social services have made this an ongoing initiative since 2001. Project C.A.R.E. uses a family consultant model to deliver comprehensive support to caregivers of those with dementia to increase quality, access, and choice for low-income rural and minority families. Family consultants offer expertise in Alzheimer's disease and related disorders and visit the homes of caregivers in crisis with timely, individualized assessment, guidance, counseling, advocacy, and educational supports. In surveys, approximately 94 percent of caregivers reported that Project C.A.R.E. services allowed them to provide care at home longer and 94 percent rated their satisfaction with the overall program above average or excellent.

## Recommendations

*The case study interviews uncovered best practices and lessons learned that should be considered when identifying and structuring caregiving interventions among various populations.*

**Convene statewide partnerships with diverse representation:** The development and application of caregiving support programs and resources is grounded in strong partnerships. Cross-sector collaborations help stakeholders collectively identify populations in greatest need of intervention, facilitate discussion, coordinate efforts, and share resources. Significant partners in such efforts include public health, community-based organizations, and consumers.

- This principle played a major role for the Alzheimer's Association California Southland Chapter in the development of the Dementia Care Network Model bringing together nonprofit service providers, program consumers, community representatives, and government entities. Through partnerships between large health organizations and community-based agencies that are trusted in their communities and have deep understanding of cultural norms, network members share knowledge, establish trust, and build on each other's strengths to develop a culturally acceptable set of supports for people with dementia and their families.
- The California Department of Public Health has also facilitated cross-sector partnerships among public and private organizations to advance shared policy, health system, and health information strategies that strengthen the 2014 [California Wellness Plan](#).
- Though the Atlanta Regional Commission maintains strong relationships across the region and state for the implementation of BRI Care Consultation, the Commission also hopes to build partnerships with public health and emergency medical services. The Commission and the Georgia Department of Public Health (DPH) are exploring potential areas of collaboration related to DPH's tele-health initiatives.

- The Aging Texas Well (ATW) initiative aims at preparing the state for the rapidly increasing population of older adults and helping older Texans age well in all aspects of their lives. A major element of the initiative is the Aging Texas Well Advisory Committee (ATWAC), which meets quarterly for members to identify and discuss policy issues related to aging. Members are appointed by the Commissioner of the Texas Department of Aging and Disability Services (DADS) and are drawn from academic institutions, advocacy organizations, service provider organizations, and staff from relevant state agencies. A DADS staff member coordinates the quarterly meetings and arranges for topic expert presentations. ATWAC members' key responsibilities are to make program and policy recommendations to DADS and to state leadership. ATW also conducts a statewide survey of older adults approximately every four years, gathering data on the needs and conditions of older Texans to inform the development of programs and policies to address those needs.

**Strengthen the caregiving workforce's capacity:** Serious illness or disability affects the family as well as the person requiring care, though family caregivers often remain the “invisible workforce” in healthcare and in long-term service and supports. With policy shifting toward home and community services and away from nursing home care, the caregiving workforce warrants a coordinated effort of support and training.

- In North Carolina, Project C.A.R.E. has been an ongoing initiative since 2001. Over the past several years, however, it has faced an unanticipated challenge in the method of providing the intervention. Project C.A.R.E. provides assistance through family consultation and support services to family members who are caring at home for a relative with dementia. The Division of Aging and Adult Services realized that while engaging working family caregivers adjustments in the intervention schedules should be considered, such as offering more night and weekend operation hours. This is in part due to the sandwich generation, caring for small children and older parents or relatives both at home.
- With high levels of staff turnover and need for training, it is difficult to stay on prescribed timelines. To maintain fidelity to their care model and have staff proficient in the necessary protocols, the Benjamin Rose Institute on Aging and the Rosalynn Carter Institute provide both initial and ongoing training for care consultants as part of the BRI Care Consultation program in Georgia. Care consultants are supervised by the Atlanta Regional Commission. Program delivery relies strictly on telephonic methods, which eliminates geographic barriers, especially among rural clients, and easily crosses regional lines.
- Caregivers may find it challenging to leave the person for whom they are providing care as the disease progresses, and for this reason, Maine statewide agencies report that recruitment for Savvy Caregiver Part II is labor intensive. The timing of the training often does not work with caregiver schedules and accepting respite and asking for help may be especially difficult given the disease's progression. These issues are particularly problematic in rural areas where there are only small clusters of Part II participants. Given these circumstances, Maine is seeking alternative technology-based delivery methods to substitute support for face-to-face encounters.

- Texas efforts to strengthen its in-home direct support workforce include the production of two realistic job previews to educate job applicants about the rewards and challenges of direct care work and encourage wavering applicants to self-select out of the selection process, without deterring applicants suited to the job. One video addresses working with older adults; the other, working with individuals who have developmental disabilities. The videos are accessible free of charge [online](#).

**Identify models of sustainability:** Limited funding pools and budget cuts require practical guides to support planning, implementation, and evaluation for sustainable program development and change.

- The Dementia Care Network was built as a scaffolding, with the ability to adjust, not as a structure to exist forever as it was initially created. A population's dementia-related needs will evolve over time, so organizations leading dementia care networks should be flexible and tweak their programs as-needed. In the areas where El Portal was implemented, support groups, several adult day healthcare programs and PACE (program of all-inclusive care for the elderly) sites trained in bilingual dementia management remain. The model's infrastructure was developed to permit growth and flexibility over time.
- The telephonic delivery of BRI Care Consultation in Georgia is beneficial as funding levels continue to be reduced and the number of those needing services rises. The average annual cost of service per caregiving family is \$1.03/day or \$376/year, while the average cost of traditional case management in Georgia is \$1,454.40/year per client. (This cost analysis is based on the Atlanta Regional Commission's care consultant salary, overhead, and fringe benefits.)
- The Texas Council on Alzheimer's Disease and Related Disorders is a legislatively mandated and appointed council formed in 1987. A key factor in the council's successful development and sustainability is the coordinating support it receives from the Texas Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP). The ADP coordinator manages council communication and contributes DSHS strategic input to its activities. The ADP coordinator also coordinates the activities of the Texas Alzheimer's Disease Partnership, which includes volunteers from across the state who form workgroups to implement activities from the Texas State Plan on Alzheimer's disease. The success of the council and the partnership is enhanced by providing collaborative environments where individuals and groups can share their different missions and goals while identifying opportunities for partnership.

## Resources and Tools

*The following resources and tools were discussed during interviews with states highlighted in this issue brief. This list is not intended to be comprehensive.*

### Clearinghouse

- The [Aging Texas Well Clearinghouse](#) is a public resource database of national and state level evidence-based programs addressing physical and mental health conditions and caregiver support.



## *Intervention Manuals*

- The California Southland Chapter of the Alzheimer's Association has prepared a [Dementia Care Network Replication Manual](#) that provides suggestions for culturally appropriate communication.
- For further information about the Savvy Caregiver Program, please review an excerpt of the [Caregiver's Manual](#).

## *Healthy Brain Initiative Road Map*

- [The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018](#), created by CDC Healthy Aging Program and the Alzheimer's Association in collaboration with other partners, outlines how state and local public health agencies and their partners can promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of care partners. Specific actions are addressed in four domains: monitor and evaluate; educate and empower the nation; develop policy and mobilize partnerships; and ensure a competent workforce.

## *State Plans*

- Each state is required to develop a state plan on aging as part of the [Older Americans Act, Section 307\(a\)](#). The aim is ensure a seamless, comprehensive service system for older adults that is responsive to their needs and preferences. The following links direct you to the state plans on aging for states featured in this issue brief: [California](#), [Georgia](#), [Maine](#), [North Carolina](#), and [Texas](#).
- In addition to their state plans on aging, [California](#), [Maine](#), and [Texas](#) have each developed specific state plans on Alzheimer's Disease and other dementia. The [Alzheimer's Association](#) houses copies of all state plans published to date as well as state-by-state comparisons of the plans' recommendations.

## *State Scorecard*

- This [Report](#) by AARP's Public Policy Institute, the Commonwealth Fund, and the SCAN Foundation displays data on state performance in the delivery of long-term services and supports for older adults and people with disabilities.

## *Toolkit*

- The Duke University Medical Center has developed an information and assistance [toolkit](#), "Working with Family Caregivers of People with Memory Disorders."

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California Department of Public Health

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Benjamin Rose Institute on Aging—MBRI  
Rosalynn Carter Institute for Caregiving

### **Maine**

Office of Aging and Disability Services  
Maine Department of Health and Human Services

### **North Carolina**

North Carolina Department of Health and Human Services, Division of Aging and Adult Services

### **Texas**

Texas Department of Aging and Disability Services



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