Chapter Five: Supporting Caregivers and Families Touched by Alzheimer's Disease and Related Dementias

As explained in Chapter 4, because of the progressive nature of Alzheimer's disease and related dementias, caring for a person with the disease is often very intensive and can require much of a caregiver's time, financial resources, and emotional and physical commitment. Families also often find themselves unprepared for the many adjustments, decisions, and preparations they have to make when faced with caring for a person with dementia. Adult children and spouses often serve as caregivers for people with Alzheimer's disease or related dementia—approximately 85% of unpaid care is provided by families, and two-thirds of family caregivers for people with dementia are women.[1, a] An estimated 448,000 people in North Carolina provided unpaid care for family members with dementia in 2014, at a value of approximately $6.2 billion.[1, b] As the disease progresses, caregivers often face increasing stress as their loved ones need additional assistance with finances, behavioral problems, wandering, and activities of daily living. Caregivers often miss work and must handle the logistics of finding additional care, and may experience increased stress, anxiety, and depression, as well as adverse physical effects.

In coming years, the burden on caregivers will greatly increase. According to AARP, census data shows that the ratio of individual caregivers (number of potential caregivers age 45-64 for each person age 80 or older) will decrease from 8.0 in 2010 to 3.9 in 2030.[2] As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families. The Task Force examined the needs of family and other unpaid caregivers and developed actionable recommendations with the goal of providing needed resources and assistance.

Caregiver Resources

Currently in North Carolina, there is a broad system of resources and supports for people providing unpaid care to family members with Alzheimer's disease or related dementia. Services such as adult day care, home delivered meal services, transportation, caregiver support groups, and respite care can provide much needed assistance to caregivers. Studies show that respite care, when coupled with education and ongoing support, reduces caregiver stress and burnout.[3] Unfortunately, caregivers often experience difficulty in learning about available resources, accessing these resources, and/or identifying the resources for which they may be eligible. In addition, the availability of resources varies by location, and services remain unaffordable for many North Carolinians.

Many organizations seek to alleviate the difficulties that caregivers face in identifying and accessing appropriate resources. The Duke Family Support Program, within Duke University, provides a broad network of supports for family caregivers. The program was the first in the state to provide family caregiver support groups, and since 1984, has functioned as a clearinghouse/database, crisis hotline, and provider of technical assistance to family caregivers and a resource to providers. The program offers confidential, personalized support in caregiving decisions, current research updates, and assistance with locating appropriate health care and other services.[4]

Alzheimer's and dementia advocacy organizations also provide valuable resources for caregivers, including information about symptoms, diagnosis, and available services. In North Carolina, the Alzheimer's Association and Alzheimer's North Carolina are both statewide nonprofit 501c3 organizations providing information on support groups, caregiver education programs, training of health care professionals, and research. Alzheimer's North Carolina raises private funding to support research efforts and provides limited respite to family caregivers in crisis. Both organizations advocate on behalf of the needs of individuals with Alzheimer's and related dementias and their caregivers. Candlelight Reflections events are held annually across the state to bring awareness to the disease and honor loved ones lost to dementia.

Project CARE (Caregiver Alternatives to Running on Empty), is the only dementia-specific state-funded service through the North Carolina Department of Health and Human Services, Division of Aging and Adult Services providing caregiver support, care management, and referrals to available services. Project CARE partners with local family caregiver support programs within each Area Agencies on Aging and other organizations in order to improve services and increase capacity.[5] Project CARE was designed and tested in North Carolina. It has become a national best practice model for providing respite services to family members who are caring at home for a loved one with Alzheimer's disease or related dementia. Project CARE uses a family consultant model to provide comprehensive support to dementia caregivers. The goal of the program is to increase quality, access, choice, and the use of respite care for low-income

---

[a] Bethel, M. Director. North Carolina Coalition on Aging. Written (email) communication, January 5, 2016.

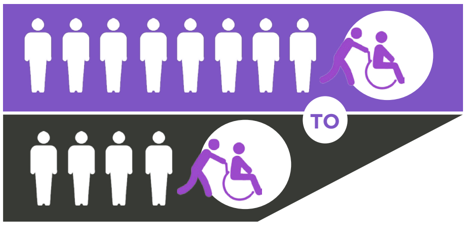
[b] "Value" is calculated using $12.17/hour in wages.

(non-Medicaid), rural and minority families caring for a person with dementia at home. However, due to a reduction in state funds in 2011 totaling $500,000, respite care through Project CARE is no longer available to family caregivers. [c]

A similar program is the New York University Caregiver Intervention program. This program combines family and individual counseling, support group referral, and ad hoc consultation. A study of this program applied in Minnesota showed a reduction of almost 50% in placement in a nursing home after two years.[6,7] Other applications of the New York University Caregiver Intervention program showed a delay in placement of 329 days compared to controls.[8] Cost modeling in Minnesota showed that if all caregivers of people with dementia received this program between 2010 and 2015, costs saved in Minnesota would have neared $1 billion and almost 20% fewer people with Alzheimer's or related dementia would have died in nursing homes.[9]

The ratio of potential caregivers for each older adult in the state* will sharply decline from

8.0 in 2010



3.9 in 2030

As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families.

*# of potential caregivers age 45-64 for each person 80 or older

Research has shown that a formal system of supports for caregivers can greatly alleviate caregiver stress, prevent social withdrawal, and improve well-being. When coupled with respite care, such systems have shown to significantly reduce depression and increase quality of life for family caregivers, of people with Alzheimer's.[7] Because such resources and supports can have a great impact on the well-being of caregivers and, thus, on people with Alzheimer's as well, it is critical that caregivers are easily and quickly able to locate and navigate the services they may need.

The National Family Caregiver Support Program (NFCSP), through Title III E of the Older Americans Act, funds a range of supports that assist caregivers including: 1) information and assistance, 2) individual counseling, organization of support groups, and training to assist caregivers in making decisions and solving problems about their caregiving roles, 3) respite care to provide temporarily relieved from their caregiving responsibilities, and 4) supplemental services, such as incontinence supplies (on a limited basis). Specific services vary by county, however these services work in conjunction with other state- and community-based services to provide a coordinated set of supports. Eligible family caregivers are those either caring for an older adult age 60 or older or providing care for a person with Alzheimer's disease or related dementia or a caregiver (who is not the birth or adoptive parent), age 55 or older, raising a related child age 18 and under or an adult with a disability.[10]

Studies have also indicated that Powerful Tools for Caregivers, a six-week curriculum designed to enhance caregiver self-care, management of emotions, self-efficacy, and use of community resources, results in improvement in all of these domains.[11, 12]

While there are specific programs in North Carolina currently working to make caregiver supports and resources easier to access and more effective in alleviating caregiver burden, these efforts often remain separate and at times difficult for families to locate, navigate, and pay for. The Task Force identified the need for a comprehensive and integrated resource for accurate, accessible, and practical information for caregivers, and for expanded resources to provide adequate services to families who need them.

Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center.

Develop a comprehensive "virtual resource center" to be maintained on the Department of Health and Human Services website. The virtual resource center will serve as an informational guide for families, professionals, care managers, and navigators including but not limited to NC 2-1-1, stakeholders, and local provider agencies. The virtual resource center will link to an updated Dementia Toolkit available on the Duke Family Support Program website. The virtual resource center and toolkit should include:

a) Information about Alzheimer's disease and related dementia, including definitions/types, prevalence, symptoms, diagnosis, etc.

b) Information on financial and logistical preparation for caregiving and end-of-life care, including care goals, decision-making needs, advanced care planning, and ways to avoid elder fraud.

---

[c] North Carolina General Assembly. Funds/Project CARE. House Bill 364. Session 2011. March 16, 2011.

c) Resources for services, including employer-based services, adult day care, caregiver respite services, and financial assistance.

d) Training resources, including hands-on caregiver training in assistance with activities of daily living.

e) Safety resources, including tips on home safety, community safety, and technological innovations (such as Safe Return or other web-based tools).

f) Resources and supports for health care providers, including information on available trainings and information on starting conversations with patients and families about financial planning and safety concerns.

g) Tools for preliminary assessment of caregiver needs, in order to provide appropriate and effective resources.

h) Availability in both web-based and hard copy format, in order to maximize accessibility for all populations.

Lead: North Carolina Division of Aging and Adult Services and Duke Family Support Program.

Partners: North Carolina Alzheimer's stakeholder organizations.

Recommendation 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through Project CARE.

Study the needs for adequate funding of Project CARE (Caregiver Alternatives to Running on Empty) as an evidence-based caregiver support service, including 'episodic' respite care, education, coaching, and caregiver training. Any initial increases in appropriations should include sufficient resources to evaluate program impacts on program goals, especially with regard to:

a) A caregiver's "intent to institutionalize" care recipients with Alzheimer's disease or related dementia, real delays in placement, and cost-savings for the Medicaid program and other state programs.

b) Show improved outcomes (i.e., delayed placement in long-term care, improved access to care, caregiver well-being, etc.) and reduced costs for individuals with dementia, their families, and payers.

c) Provide a full analysis and recommendation to the General Assembly for initial pilot funding for evidence-based programs within selected communities, with the possibility of recurring funding after additional results and outcomes analysis.

Lead: North Carolina Division of Aging and Adult Services.

Partners: North Carolina General Assembly and Fiscal Research Division.

INDIVIDUAL **SPOTLIGHT**

> **"After my diagnosis of Alzheimer's, I have had to re-create myself. Living out of my heart and less out of my head allows me to live in the now. I do not trust my head to remember or to make good decisions as I once did. One day I will not be able to recall the names of the people I love. So, I have told my children, family and friends that I am placing them in my heart where they will always be. Living in the now and placing them in my heart takes away some of the burden of Alzheimer's.**
>
> **James Hyde, Black Mountain, NC**

Access to Accurate and Appropriate Long-Term Services and Supports

North Carolina is working toward making it easier for individuals who need long-term services and supports and their caregivers to learn about the full array of services available and access the help they need. Long-term services and supports help address both the clinical and non-clinical needs of people with chronic illness or disability who need ongoing assistance with daily living. (See Chapter 4 for additional information on long-term services and supports.) These services encompass a wide array of programs, and are provided through private and public agencies. Because of the complicated network of programs, these services are often difficult for individuals or families to access. People trying to access the multitude of services and supports frequently find themselves confronted with a maze of agencies, organizations, and programmatic requirements at a time they may be in crisis. They often require assistance in accessing the appropriate service to meet their current and future needs.[d]

---

[d] Solovieff T. Project Director. North Carolina Department of Health and Human Services. Written (email) communication, November 9, 2015.

> **“Applications of the New York University Caregiver Intervention program showed a delay in placement of 329 days.**

To this end, North Carolina is in the process of developing plans to implement a “No Wrong Door” system of access for long-term services and supports, the primary objective of which is to help meet families’ needs by providing information, education, and connection to services. No Wrong Door will establish a statewide informational platform to serve as a one-stop connection to information and assistance navigating long-term services and supports, Alzheimer’s and dementia related services and supports, and/or other health and human services and supports.[e]

A primary strategy of No Wrong Door is a continued and enhanced partnership with NC 2-1-1. NC 2-1-1 was established and is maintained by United Way of North Carolina and is funded through a combination of public and private investment. United Way partners with state stakeholders to operate the NC 2-1-1 system, which provides access, via telephone and internet, to many services and supports, including health and human services and government programs.[13] Current and potential features of NC 2-1-1 include:

- easy to remember toll-free hotline
- educational website including brief overview of topics, points the reader to relevant service providers and web links to additional details
- 24/7 information and referral services, answered by trained professionals
- multi-language translation services
- comprehensive statewide database of health and human services in the community; to include specific Alzheimer’s and dementia related services and supports
- reporting and analytical capabilities to track reasons for calls and referrals made[13]

With a common goal of improving access statewide to appropriate care, resources, and supports for caregivers of individuals with dementia, the Task Force recommends additional state support for North Carolina’s No Wrong Door system through a partnership with NC 2-1-1.

Recommendation 5.3: Continue No Wrong Door Initiative through a collaboration with NC 2-1-1.

Provide an annual investment of $200,000 for management of state involvement with the No Wrong Door initiative and “virtual front door” access provided through partnership with NC 2-1-1. NC 2-1-1 will provide the infrastructure for the No Wrong Door system, building on the existing information management platform. This funding should support two full-time staff positions to oversee continued No Wrong Door development and implementation, migration of Alzheimer’s disease and dementia-related community resources to enhance the existing NC 2-1-1 database, manage Alzheimer’s disease and dementia-related stakeholder partnerships, and provide planning for evaluation, sustainability, and further statewide scaling. As part of this work, the Division of Aging and Adult Services should:

a) Develop infrastructure for state and local government involvement with NC 2-1-1 on dementia-specific resources.

b) Identify and manage partnerships with organizations including the Area Agencies on Aging, Department of Social Services, aging transition services, Just One Call (Mecklenburg County), caregiver representatives, and other community resource organizations to ensure the integrity of Alzheimer’s disease and dementia-specific information provided to NC 2-1-1 on available services and resources is accurate, up-to-date, and continuously monitored.

c) Partner with NC 2-1-1 leadership to identify available outside funding sources to support expansion of information management system, thereby improving access and referral support to older adults and/or people with dementia.

d) Work with NC 2-1-1 leadership to expand and enhance systems integration capabilities, develop controlled marketing strategies, website enhancement, training for call center staff, technology opportunities (through mobile apps and others), and development of reporting and quality assurance measurements.

e) Partner with aging and dementia advocacy organizations, including the Alzheimer’s Association, Alzheimer’s North Carolina, Area Agencies on Aging, local Departments of Social Services, and

---

[e] Solovieff T. Project Director. North Carolina Department of Health and Human Services. Written (email) communication, November 9, 2015.

AARP North Carolina, to increase awareness of NC 2-1-1 as a primary resource for health care needs, home- and community-based services, and caregiver support and assistance.

f) Coordinate training for NC 2-1-1 staff in working with individuals or families with Alzheimer's disease or related dementias and/or engaging dementia specialists to serve as NC 2-1-1 staff.

Lead: General Assembly.

Partners: Division of Aging and Adult Services and United Way of North Carolina.

Caregivers and Employment

Many caregivers for people with Alzheimer's disease and related dementia face logistical and financial difficulties in caring for their family members, especially with regards to employment. Because people with Alzheimer's disease or related dementias require more care over time, family caregivers often find themselves having to be absent from work or leave the workforce completely in order to attend to their family members' needs.

> **"In North Carolina, more than 75% of family caregivers have had to adjust work schedules to care for family members.**

Nationwide, the average caregiver is a 49 year-old woman, caring for her 60 year old mother who does not live with her. She is married and employed.[14] In the United States, more than 60% of family caregivers (for all conditions) are employed, and in North Carolina, more than 75% of family caregivers have had to adjust work schedules to care for family members.[f,2] Fifteen percent of family caregivers have to give up employment entirely in order to care for a family member. These changes often result in lowered earnings, reduced Social Security benefits, and loss of other employment-related benefits such as health insurance and retirement savings.[2]

Caregiving can also have a negative impact on employers. Nationally, employers report a productivity loss of nearly $33.6 billion, with an average annual cost per full-time employee caregiver at $2,110.[15] Employers can contribute to relieving stress on their caregiver employees and also recoup productivity losses through supportive benefits such as enhanced resource referral programs and flexible and accommodating leave policies. While more employers are beginning to offer such policies, there is more work to be done. In the 2015 North Carolina legislative session, AARP North Carolina, in collaboration with a broad array of partners, sought legislation that would allow employees to use existing sick leave benefits for caregiving for family members, and also to allow employees to take short, unpaid leave for family members' illness, injury, or medical needs. The bill, House Bill 816, was rewritten to broadly study the needs of working caregivers. Passed unanimously by the House, this bill is currently in the Senate Rules Committee.[g]

Recommendation 5.4: Enhance employer policies to support family caregivers.

Partner with employer stakeholders and business interests to develop policies to encourage active employer participation in support for employee caregivers. This should include:

a) Education for employers about Alzheimer's disease and related dementia, the role of family caregivers and support for additional promotion of caregiver-friendly policies.

b) Policies to support employee caregivers, including options such as flextime, paid and unpaid family leave, non-discrimination against caregivers in workplace, telecommuting, referral programs, respite services, on-site support groups, awareness of available benefits (i.e., Family Medical Leave Act eligibility), expansion of the definition of family for caregiving and leave-related policies, and specialized employee assistance programs.

c) Identification of corporate/employer champions to promote benefits of supportive employer policies to economic interests, as well as employee caregivers' interests.

d) Encourage passing of House Bill 816 through the North Carolina Senate, in order to study the needs of working family caregivers.

Lead: AARP North Carolina, Alzheimer's North Carolina, the Alzheimer's Association, the Association for Home and Hospice Care, and the North Carolina General Assembly.

Partners: Employer stakeholders and business interests, including North Carolina Chamber of Commerce and the Society for Human Resources Management.

---

[f] This is for all conditions, not just Alzheimer's/dementia-specific.

[g] North Carolina General Assembly. House DRH10314-LR-137A. House Bill 816. Session 2015. April 14, 2015.

Home- and Community-Based Services

For the purposes of this report, Home and Community-Based Services refer to services funded through state and federal dollars administered at the county level. These services are generally designed to supplement and improve care provided in the home of older adults, to assist unpaid caregivers caring for loved ones in the home, and to delay institutionalization. These programs may include services such as in-home care, nutrition programs such as home-delivered meals, respite programs, adult day care, and transportation services. Funding streams for these programs vary, as does eligibility criteria.

Many of these services are those that, if provided, could prevent or delay institutionalization. An AARP analysis of home- and community-based services provided in 25 states between 2005 and 2012 showed overwhelming evidence that investment in expanded home- and community-based services contains costs and slows cost growth, largely due to savings from delayed or prevented institutionalization.[16] For respite care specifically, research has shown that an increase of $100 toward respite care produced approximately a one-week delay in institutionalization.[17]

Home and Community Care Block Grant

The North Carolina General Assembly established the Home and Community Care Block Grant in 1992 to provide home- and community-based services to older adults in North Carolina.[h] These services target non-Medicaid eligible older adults in the state. The North Carolina Division of Aging and Adult Services administers the block grant and the Area Agencies on Aging disburse funding to counties. Funding is combined with several federal sources including Title III-B funding for supportive services, Title III-C-1 funds for congregate meals, Title-III-C-2 funding for home-delivered meals, Title III-D funds for frail elderly services, Older Americans Act funds for older adult services, and state appropriations for older adult services. The Federal Older Americans Act provides about 49% of North Carolina's Home and Community Care Block Grant funds with the remaining 51% provided in recurring state appropriations.[i] Total aggregate funding has remained flat at $61 million over the last three years, despite increasing numbers of older adult North Carolinians and increasing costs of services.[18]

> **“Research has shown that an increase of $100 toward respite care produced approximately a one-week delay in institutionalization.**

In North Carolina in fiscal year 2015, there were approximately 9,700 individuals statewide on the waiting list for services through the Home and Community Care Block Grant. The total cost for providing needed services for those on the waiting list would be approximately $19.6 million.[j]

North Carolina has combined a variety of state and federal funds to provide services through the Home and Community Care Block Grant. Combining funds results in greater administrative efficiency. However, it also means that all provided services must comply with the Older Americans Act, which requires that states do not allow cost-sharing or charge for services paid for with Home and Community Care Block Grant funds. Programs are allowed only to offer the opportunity for service recipients to make voluntary contributions. One option to increase the number of individuals served would be to unbundle some state funding from this program to offer services on an income-based sliding scale to individuals with varying levels of ability to pay.[l]

Recommendation 5.5: Examine outcomes and impact of home- and community-based services programs.

In order to maximize state resources, the lead agency should examine home and community based programs that have shown improved outcomes (such as delayed placement in long term care, improved access to care, and improved caregiver wellbeing) and reduced costs for individuals with Alzheimer's disease or related dementias, their families, and payers. Lead agency should:

a) Analyze the impact of home- and community-based services on overall health care costs, including impact on Medicare and Medicaid costs, and caregiver/family economic and well-being costs, of increasing the number of individuals able to access home- and community-based services, and/or age in place. (Potential programs may include financial provisions for personal care services and missed work days, specialized medical supplies and home safety technologies, and respite care.)

---

[h] NCGS § 143B-181.1(a) (11).

[i] Hensley M. Alzheimer's Support Specialist. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. September 28, 2015.

[j] Reddy S, Hayden L. Planner/Evaluator. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. February 8, 2016.

b) Include evaluation costs in funding recommendations to determine whether service providers met outcome goals, including waiting lists for services.

c) Conduct an analysis of modifying the Home and Community Care Block Grant configuration. The analysis should include:

  i. Review of current allocation methodology and payment to allow for consumer cost-sharing.

  ii. Detailed analysis of the process by which the modifications would be made to existing state statutes (i.e., North Carolina General Assembly approval).

  iii. Estimated potential expansion of services from revenue generated from instituting a sliding fee for service (income-based) and return on investment analysis.

Lead: North Carolina Department of Health and Human Services.

Medicaid Coverage of Home- and Community-Based Services

Established in 1981 under section 1915 (c) of the Social Security Act, Medicaid Home- and Community-Based Service (HCBS) waivers—including North Carolina's Community Alternatives Program for Disabled Adults (CAP/DA) and CAP/Choice waivers—have become increasingly popular as states look to reduce Medicaid spending on long-term services and supports delivered in institutional settings. The CAP/DA waiver and the Community Alternatives Program for Choice (CAP/Choice) covers services including adult day care, personal care, and caregiver respite services.[19] CAP/Choice allows individuals to pay family members for providing home-based care.[20] (See Chapter 4 for additional information on Medicaid waivers.)

In December 2013, North Carolina had 11,214 approved CAP/DA slots across the state, with a waitlist of over 8,000 individuals. As of early 2014, CAP/DA lead agencies are required to utilize at least 95% of their available CAP/DA slots and this utilization rate is reviewed quarterly.[21] Many counties or service providers may, technically, have "open" slots for individuals seeking services through waivers, but the slots cannot be filled due to lack of local funding.

Medicaid-funded HCBS programs operate under two conditions:

1. To receive an HCBS waiver a person must meet the eligibility criteria for institutional care under Medicaid (see Chapter 4).
2. An HCBS program must be cost-neutral, meaning that for people meeting the same level of institutional eligibility, the average per-person HCBS payment must not exceed the average per-person institutional payment.

Recent studies have shown that HCBS programs are likely to be cost-effective over time. On the individual level, an HCBS waiver costs Medicaid far less than institutional care—a difference of about $44,000 in 2006.[22] Evidence shows that while states are in the process of expanding HCBS programs, Medicaid spending on long-term care will increase more rapidly than in states with small HCBS services. However, once large HCBS programs are established, Medicaid long-term care spending increases at a slower rate than in states with small HCBS programs. States with large HCBS programs experienced an inflation-adjusted net reduction in Medicaid expenditures on nursing homes of about 15% between 1995 and 2005.[23] HCBS program expansion can help save Medicaid money over time by slowing the growth of long-term care expenditures.

States have begun to look beyond HCBS waivers to different models for delivering community-based services, including consumer-directed care and capitated payment models. The evidence on Medicaid costs for these models is mixed. On the whole, these alternative programs have elevated patient and caregiver satisfaction above institutional care satisfaction. Some have demonstrated improved health outcomes—most notably the Program of All-Inclusive Care for the Elderly (PACE), which uses capitated Medicaid and Medicare payments to provide community-based integrated care. Some studies have found that Medicaid costs increased as a result of these programs, while others have found cost reductions.[24] Individuals on the waitlists for services through CAP/DA may be referred to PACE programs if they are locally available.[21]

CAREGIVER **SPOTLIGHT**

> **Now that my husband is in assisted living, the loss of income has been devastating for me. A guardianship was granted in June 2015. It is hard seeing and accepting the diagnosis. My health deteriorated after a heart attack, I lost my job, and stress is unreal.**
>
> **Caregiver, Jackson County, NC**

PACE, Cash and Counseling, Wisconsin Family Care, Minnesota Senior Health Options, S/HMO II, and Medicare Alzheimer's Demonstrations are among the community-based programs that have demonstrated higher Medicaid costs than traditional institutional care. Arizona's Long-Term Care System, a statewide mandatory managed care program that incentivizes HCBS, and Texas STAR+PLUS have produced cost savings to Medicaid. Figure 5.1 shows additional data on cost savings from state programs that aim to reduce long-term care costs through delaying institutionalization.

Figure 5.1: State Data on Impact of Delays in Institutionalization through Expanded Home- and Community-Based Services

State	Program Description	Evidence of Impact on Cost and Delays in Institutionalization
Arkansas[25]	Arkansas Community Connector is a three-year Medicaid demonstration program. The program identified individuals at risk for entering nursing homes (using Medicaid criteria) and linked them with community-based services and supports. Medicaid spending for individuals receiving care coordination services was compared with a control group who did not receive the services.	The intervention resulted in a 23.8% average reduction in annual Medicaid spending per participant. Savings equaled $2.619 million for the 919 individuals included in the study's intervention group, a $3 return on investment per $1 invested.
Connecticut[26]	Connecticut Home Care Program for Elders includes a Medicaid waiver program that provides home- and community-based services to individuals who would otherwise require full-time nursing facility care.	A cost-effectiveness model that estimated annual savings of nearly $107 million compared with serving participants in a nursing facility. 19,932 individuals received services through the Medicaid waiver program.
Georgia[27]	SOURCE (Service Options Using Resources in a Community Environment) is a Medicaid waiver program that provides care management and home- and community-based services to participants who would otherwise require nursing facility care.	In fiscal year 2007, the average monthly per-participant cost was $1,538; the average monthly per-recipient cost of nursing facility placement in Georgia was $4,369. Cost effectiveness was demonstrated across different levels of care needs. There was a reduction in percentage of total Medicaid expenditures for institutional care versus community-based care (73% institutional care in FY 2005; 64% institutional care in FY 2008).
Maryland[28]	Money Follows the Person helps Medicaid recipients navigate the payment transition from nursing facilities to home-based care and provides Medicaid waivers for aging in place, covering long-term services and supports received in a home setting.	Comparing spending for pre and post Money Follows the Person (MFP)transitions, Medicaid costs declined following transitions to the community. Pre-transition costs for FY 2008–FY 2010 were $9,114 per-member per-month, compared with $5,957 per month following MFP transition. More MFP-transitioned individuals reported higher quality of life.
West Virginia[29]	West Virginia implemented Money Follows the Person in 2011.	Projected savings between $57 million and $62 million over a 10-year period from transitioning between 75 and 150 individuals from nursing facilities to home and community-based services.
Rhode Island[30]	Rhode Island's Global Waiver program provides Medicaid-eligible recipients with home- and community-based services, and attempts to shift spending on long-term services and supports to home- and community-based services and decrease or delay institutionalization.	The Global Waiver program resulted in Medicaid savings on long-term services and supports of $35.7 million over the three-year study period (for an average of 8,681 beneficiaries per year). For those enrolled in care management services, data showed improved access to physicians and decreased emergency department utilization, resulting in estimated savings of about $5 million in FY 2010.

Structured Family Caregiving is a model of care administered through a private company called Caregiver Homes. This model is made available through Medicaid waiver programs and provides professional and financial support to family and other caregivers, such as neighbors or friends, who are providing full-time care. Caregivers receive individualized support from nurses and social workers, including coaching on how to perform personal care and manage challenging behaviors. Caregivers are required to complete daily health and welfare status updates to inform the care team of the status of the person under his or her care. The stipend is non-taxable income and is less than half the cost of skilled nursing facility services. In the first year that Rhode Island offered this program, 115 people signed up and the state reported saving over $1.5 million. Structured Family Caregiving is currently available as a Medicaid service in seven states. [l, 31]

The evidence is mixed on the cost-effectiveness of HCBS and other community-based care models. Some populations are unequivocally more cost-effective to serve in the home or community. For example, state HCBS funding significantly decreases the likelihood of institutionalization for childless seniors.[32] Increased state spending on HCBS waivers also reduces the number of low-income individuals in nursing homes.[33]

---

[l] Hendley R. Alzheimer's Support Specialist. Caregiver Homes. Written (email) communication. February 8, 2016.

The Patient Protection and Affordable Care Act (ACA) also includes several provisions designed to shift long-term services away from institutional care. Currently, North Carolina only participates in one of the ACA rebalancing initiatives, the Money Follows the Person Grant.[34] This initiative allows for Medicaid eligible people who wish to leave institutional care for community care to do so with HCBS funding from PACE or CAP.[35] Data from the North Carolina Department of Health and Human Services, Division of Medical Assistance shows a reduction of 32% in Medicaid spending for individuals who transitioned to community-based care from an institutional setting through Money Follows the Person.[m,n]

> **“Data from the North Carolina Department of Health and Human Services, Division of Medical Assistance shows a reduction of 32% in Medicaid spending for individuals who transitioned to community-based care from an institutional setting through Money Follows the Person.**

Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.

Provide additional funding for the existing Medicaid Home- and Community-Based Services waiver program (including CAP/DA and CAP/Choice) to include additional services for individuals with Alzheimer's disease and their families. Expansion should:

a) Have the ultimate goals of reducing the waitlist for receipt of services and delaying placement in institutional long-term care. The Dual Eligibles Work Group[o] should also examine root causes of waitlists and identify ways to reduce them.

b) Allow greater flexibility to cover adult day care services and group respite.

c) Under reform, allow managed care organizations and provider-led entities to contract for community-based services using a flexible waiver.

d) Include provisions for local community work on increasing awareness and navigation of available services for people with dementia and their caregivers, including limitations and provisions of Caregiver Directed Vouchers.

e) Include provisions to address barriers faced by county Departments of Social Services in providing immediate services.

f) Include additional funding for evaluation of impact of expansion on waitlist, outcomes, and health care costs (including impact on Medicaid costs).

Lead: North Carolina General Assembly

In addition to identifying expanded funding opportunities, particularly those that will result in savings to the state for long-term services and supports, there is also an urgent need to coordinate home- and community-based services funded at the state level through Medicaid, Area Agencies on Aging, county agencies, Medicare, and private insurers. As the aging population grows, the number of people with Alzheimer's disease or related dementias increases, and the number of available caregivers declines, North Carolina state agencies must look forward in order to avoid a crisis. Services are available to some individuals and families depending on household income, insurance coverage, and geography, but state stakeholders must develop a comprehensive understanding of available services, service gaps, and the most efficient, equitable, and affordable way to connect individuals to services.

Recommendation 5.7: Implement best practices for the integration and coordination of home- and community-based services.

Identify best practices for the integration and coordination of home- and community-based services,

---

[m] Hensley M. Alzheimer's Support Specialist. Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Written (email) communication. February 18, 2016.

[n] Percentage includes individuals who qualify under aging/physical disability only (not those who quality with intellectual/developmental disability).

[o] Dual eligibles" refers to 10.2 million Americans who qualify for coverage under both Medicare and Medicaid. These individuals are among the most disabled, chronically ill, and costly coverage recipients. On average, health care costs for the dual eligible population are 60% more than for non-dual eligible individuals. Approximately half of dual eligible qualify for Medicare because of disability rather than age. Almost one-fifth have three or more chronic conditions. More than 40% use long-term services or supports. In North Carolina, the Dual Eligibles Work Group was mandated by the Medicaid Transformation and Reorganization legislation in 2015

and work statewide to implement these practices and improve awareness of available services. Potential strategies may include using new models of care such as the Transformation Innovations Center under Medicaid reform to identify best practices and deliver improved services; expanding of online resources (i.e., dementia toolkit, online training programs, etc.); connecting services with NC 2-1-1, (see Recommendation 5.3); integration of health services and community-based services; and expanding training for health care providers, care managers, and options counselors on existing services, waiver programs, and financial assistance.

Lead: North Carolina Division of Aging and Adult Services.

Partners: State Medicaid Agency and county Departments of Social Services.

REFERENCES

1. Alzheimer's Association. *2015 Alzheimer's Disease Facts and Figures*. Chicago, IL: Alzheimer's Association; 2015. https://www.alz.org/facts/downloads/facts_figures_2015.pdf. Accessed November 1, 2015.

2. AARP North Carolina. *Supporting Family Caregivers in North Carolina*. Raleigh, NC: AARP North Carolina; 2015. http://www.nciom.org/wp-content/uploads/2015/02/2015-Caregivers-Fact-Sheet.pdf. Accessed October 10, 2015.

3. ARCH National Respite Network and Research Center. *Annotated Bibliography of Respite and Crisis Care Studies*, 3rd Edition. Chapel Hill, NC: ARCH National Respite Network and Research Center; 2014. http://archrespite.org/images/docs/Bibliographies/Annotated_Bibliography_For_Print.pdf. Accessed November 14, 2015.

4. Duke Family Support Program. Duke Alzheimer's Family Support Program website. http://www.dukefamilysupport.org. Accessed November 16, 2015.

5. North Carolina Division of Aging and Adult Services. Project CARE (Caregiver Support). North Carolina Department of Health and Human Services website. http://www.ncdhhs.gov/assistance/adult-services/project-care. Accessed December 10, 2015.

6. Gaugler JE, Reese M, Mittelman MS. Effects of the NYU Caregiver Intervention-adult child on residential care placement. *Gerontologist*. 2013;53(6):985-997.

7. Gaugler JE, Reese M, Mittelman MS. Effects of the Minnesota adaptation of the NYU Caregiver Intervention on primary subjective stress of adult child caregivers of persons with dementia. *Gerontologist*. 2015.

8. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA*. 1996;276(21):1725-1731.

9. Long KH, Moriarty JP, Mittelman MS, Foldes SS. Estimating the potential cost savings from the New York University Caregiver Intervention in Minnesota. *Health Aff (Millwood)*. 2014;33(4):596-604.

10. Administration for Community Living. National Family Caregiver Support Program (OAA Title IIIE). Administration on Aging website. http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/. Accessed February 18, 2016.

11. Savundranayagam MY, Montgomery RJ, Kosloski K, Little TD. Impact of a psychoeducational program on three types of caregiver burden among spouses. *Int J Geriatr Psychiatry*. 2011;26(4):388-396.

12. Won CW, Fitts SS, Favaro S, Olsen P, Phelan EA. Community-based "powerful tools" intervention enhances health of caregivers. *Arch Gerontol Geriatr*. 2008;46(1):89-100.

13. Marx L. Overview of NC 2-1-1. Presented to: NCIOM Task Force on Alzheimer's Disease and Related Dementia; October 30, 2015; Morrisville, NC. http://www.nciom.org/wp-content/uploads/2015/05/Marx_October-30-Presentation-SLIDES-ONLY.pdf. Accessed January 5, 2016.

14. Family Caregiver Alliance. Women and caregiving: facts and figures. Family Caregiver Alliance website. https://www.caregiver.org/women-and-caregiving-facts-and-figures. Accessed February 18, 2016.

15. Feinberg L, Choula R. *Understanding the Impact of Family Caregiving on Work*. Washington DC: AARP Public Policy Institute; 2012. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf. Accessed February 15, 2016.

16. Fox-Grage W, Walls J. *State Studies Find Home and Community-Based Services to be Cost-Effective*. Washington, DC: AARP Public Policy Institute; 2013.

17. Kosloski K, Montgomery RJ. The impact of respite use on nursing home placement. *Gerontologist*. 1995;35(1):67-74.

18. North Carolina Senior Tar Heel Legislature. 2016 NCSTHL priorities. North Carolina Senior Tar Heel Legislature website. http://www.ncsthl.org/priorities.html. Accessed December 14, 2015.

19. North Carolina Division of Medical Assistance. Community Alternatives Program for Disabled Adults. North Carolina Department of Health and Human Services website. https://dma.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-disabled-adults. Accessed December 15, 2015.

20. Paying for Senior Care. North Carolina Community Alternatives Program for Disabled Adults Waiver (CAP/DA). Paying for Senior Care website. https://www.payingforseniorcare.com/medicaid-waivers/nc-community-alternatives-program-for-disabled-adults.html. Published April 2015. Accessed November 14, 2015.

21. Bratts-Brown, W. Division of Medical Assistance, North Carolina Department of Health and Human Services. CAP/DA slot utilization and waitlist management. December 27, 2013.

22. Kitchener M, Hernandez M, Ng T, Harrington C. Residential care provision in medicaid home- and community-based waivers: a national study of program trends. *Gerontologist*. 2006;46(2):165-172.

23. Kaye HS, LaPlante MP, Harrington C. Do noninstitutional long-term care services reduce Medicaid spending? *Health Aff (Millwood)*. 2009;28(1):262-272.

24. Grabowski DC. The cost-effectiveness of noninstitutional long-term care services: review and synthesis of the most recent evidence. *Med Care Res Rev*. 2006;63(1):3-28.

REFERENCES

25. Felix HC, Mays GP, Stewart MK, Cottoms N, Olson M. The care span: Medicaid savings resulted when community health workers matched those with needs to home and community care. *Health Aff (Millwood)*. 2011;30(7):1366-1374.

26. Connecticut Department of Social Services. *Home Care at a Glance: SFY 2010 Report to the Legislature*. Hartford, CT: Connecticut Department of Social Services; 2010. http://www.ct.gov/dss/lib/dss/pdfs/reports/sfy_2010_ct_home_care_annual_report.pdf. Accessed February 15, 2016.

27. Myers & Stauffer LLC. Georgia Department of Community Health. Final Report on SOURCE Program Cost Effectiveness. http://www.myfloridahouse.gov/ sections/Documents/loaddoc.aspx?PublicationType=Committees&CommitteeId=2546&Session=2010&DocumentType=Action%20Packets&FileName=SPCSEP_Actn_3-4- 2010.pdf. Published July 14, 2006. Accessed February 15, 2016.

28. The Hilltop Institute. *Medicaid Long-Term Services and Supports in Maryland: Money Follows the Person Metrics Summary*. Baltimore, MD: The Hilltop Institute; 2011. http://www.hilltopinstitute.org/publications/MFPMetricsQoLSurveyResponsesJanuary2011.pdf. Accessed February 15, 2016.

29. Public Consulting Group. Money Follows the Person' and Long Term Care System Rebalancing Study; Executive Summary. http://www.wvdhhr.org/oig/olmstead/ rebalancing%20and%20mfp/rebalancing%20and%20mfp%20full%20length%20study %20report.pdf. Published August 8, 2008. Accessed February 15, 2016.

30. The Lewin Group. *An Independent Evaluation of Rhode Island's Global Waiver*. Falls Church, VA: The Lewin Group; 2011. http://www.ohhs.ri.gov/documents/documents11/Lewin_report_12_6_11.pdf. Accessed February 15, 2016.

31. Caregiver Homes. Seniorlink. Caregiver Homes website. http://caregiverhomes.com/about/seniorlink. Accessed December 14, 2015.

32. Muramatsu N, Yin H, Campbell RT, Hoyem RL, Jacob MA, Ross CO. Risk of nursing home admission among older Americans: does states' spending on home- and community-based services matter? *J Gerontol B Psychol Sci Soc Sci*. 2007;62(3):S169-178.

33. Hahn S. North Carolina family caregivers provide $13.4 billion in unpaid care according to AARP study. AARP North Carolina website. http://states.aarp.org/north-carolina-family-caregivers-provide-13-4-billion-in-unpaid-care-according-to-aarp-study/. Published July 16, 2015. Accessed November 10, 2015.

34. Watts MO, Reaves EL, Musumeci M. *Money Follows the Person: A 2015 State Survey of Transitions, Services, and Costs*. Washington DC: The Henry J. Kaiser Family Foundation; 2015. http://kff.org/medicaid/report/money-follows-the-person-a-2015-state-survey-of-transitions-services-and-costs/. Accessed December 17, 2015.

35. North Carolina Division of Medical Assistance. Money Follows the Person. North Carolina Department of Health and Human Services website. https://www2.ncdhhs.gov/dma/MoneyFollows/. Accessed December 17, 2015.

36. Morgan RB. Medicare-Medicaid Dual-Eligibles. National Conference of State Legislatures website. http://www.ncsl.org/research/health/medicare-medicaid-dual-eligibles.aspx. Published November 4, 2013. Accessed February 12, 2016.