

Virginia Family Caregiver Stakeholder Workgroup:

# Recommendations for Improving Family Caregiver Support in Virginia 2018

Revised to include DARS Analysis and Work Plan

September 1, 2018



VIRGINIA DEPARTMENT FOR AGING  
AND REHABILITATIVE SERVICES

# Recognize ♦ Support ♦ Transform

## TABLE OF CONTENTS

<b>DARS ANALYSIS AND WORKPLAN</b>	<b>R-I</b>
<b>EXECUTIVE SUMMARY</b>	<b>II</b>
<b>FINDINGS</b>	<b>1</b>
<b>RECOMMENDATIONS</b>	<b>4</b>
<b>GOAL I: FAMILY CENTERED CARE</b>	<b>4</b>
Recommendation 1 .....	6
<b>GOAL II: ENGAGE FAMILY CAREGIVERS IN CARE</b>	<b>6</b>
Recommendation 2 .....	7
<b>GOAL III: TRAINING AND CAPACITY</b>	<b>7</b>
Recommendation 3 .....	8
Recommendation 4 .....	9
<b>GOAL IV: CAREGIVER STATE INCOME TAX CREDIT</b>	<b>10</b>
Recommendation 5 .....	10
<b>GOAL V: TELEHEALTH</b>	<b>11</b>
Recommendation 6 .....	12
<b>GOAL VI: RESPITE</b>	<b>12</b>
Recommendation 7 .....	14
<b>GOAL VII: INFORMATION AND REFERRAL</b>	<b>14</b>
Recommendation 8 .....	16
Recommendation 9 .....	16
<b>GOAL VIII: TECHNOLOGY INNOVATION</b>	<b>16</b>
Recommendation 10 .....	18
<b>GOAL IX: CAREGIVERS IN THE WORKPLACE</b>	<b>18</b>
Recommendation 11 .....	21
Recommendation 12 .....	21
Recommendation 13 .....	21
<b>GOAL X: DATA AND ADVOCACY</b>	<b>22</b>
Recommendation 14 .....	22
Recommendation 15 .....	23
<b>CONCLUSION</b>	<b>23</b>
<b>APPENDIX A PROMISING PRACTICES FOR INCLUDING FAMILY CAREGIVER SUPPORT IN MLTSS</b>	<b>24</b>
<b>APPENDIX B CAREGIVER RESOURCES</b>	<b>25</b>
<b>APPENDIX C VIRGINIA FAMILY CAREGIVER STAKEHOLDER WORKGROUP</b>	<b>26</b>
<b>APPENDIX D LETTERS OF SUPPORT</b>	<b>27</b>

# Recognize ♦ Support ♦ Transform

## DARS ANALYSIS AND WORK PLAN

On June 14, 2017, AARP released *The Long-Term Services and Supports Scorecard* that ranked Virginia 47<sup>th</sup> in Support for Family Caregivers. The Department for Aging and Rehabilitative Services (DARS) convened the Virginia Family Caregiver Stakeholder Workgroup beginning in July 2017 in response to requests from legislators and advocates to study and develop ways for the Commonwealth to encourage and support families and communities in assisting aging adults and individuals with disabilities. The purpose of this work plan is to address the recommendations developed by the workgroup and to lay out a plan for DARS' collaborative engagement with sister state agencies.

### VIRGINIA DEPARTMENT OF HEALTH (VDH)

---

**Action: DARS will seek assistance of VDH to raise awareness of the importance of the CARE Act, as well as the Behavioral Risk Factor Surveillance System (BRFSS) Optional Caregiver Module.**

In 2015, the Caregiver Advise, Record, and Enable (CARE) Act (Virginia Code § 32.1-137.03) provides that, upon discharge of a patient from an inpatient hospital stay, a patient can designate a caregiver. The hospital is required to contact the designated caregiver, notify him or her of the hospital discharge and the discharge plan, and offer the caregiver instruction in aftercare tasks.

**Recommendation 1:** Hospitals should collect data on the number of caregiver designations, notifications, and instruction. This data can then be analyzed to track the implementation of the CARE Act and determine its efficacy. Health systems should be encouraged to include the caregiver designation in their electronic medical records (EMR).

#### Possible Implementation Actions

1. Commonwealth work with the Virginia Hospital & Healthcare Association (VHHA) to examine development and implementation of a data collection process to gather data about family caregiver designations.
2. Examine feasibility of VDH and VHHA training hospitals on the CARE Act at conferences and conduct webinars for hospital staff.
3. Commonwealth consider amending regulations to obtain data collection and/or EMR caregiver designations.

*From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Crisis* recommends using the optional BRFSS Caregiver Module to track family caregiving prevalence data in the states. VDH did this in 2014-2015 with a DARS application on behalf of the Alzheimer's Disease and Related Disorders Commission with funding from the Alzheimer's Association.

## Recognize ♦ Support ♦ Transform

**Recommendation 14:** DARS seeks the inclusion of the optional Caregiver Module questions in the Behavioral Risk Factor Surveillance System administered through the Virginia Department of Health for 2019 to produce longitudinal data for trend analysis with the 2015 BRFSS data. The optional Caregiver Module should then be collected every three years thereafter.

1. Discuss the feasibility of including the optional Caregiver Module in the 2019 BRFSS.
2. If this is feasible, fund and include the Caregiver Module in the 2019 BRFSS. Applications are due October 2018.

UPDATE: DARS will collaborate with other groups to apply for the inclusion of the optional Caregiver Module questions in the 2019 Behavioral Risk Factor Surveillance System.

### **DEPARTMENT OF MEDICAL ASSISTANCE SERVICES (DMAS)**

---

**Action: DARS will meet with DMAS about Commonwealth Coordinated Care (CCC) Plus Managed Care Organization (MCO) contracts including caregiver assessments and supports and Medicaid coverage of telehealth services through the home health benefit.**

A report released by the AARP Public Policy Institute in November 2016 emphasizes that family caregivers are an invaluable part of the care team and often make the difference between an insurance beneficiary remaining in the community or being institutionalized. As Virginia Medicaid shifts to Managed Long Term Services and Supports (MLTSS), a key component must not be left out of the equation: family caregivers.

**Recommendation 2:** Include a comprehensive assessment of the family caregiver's health, well-being, and needs in Virginia's CCC Plus MCO contracts for MLTSS. MCO care coordinators should make referrals to supports for caregivers including training, education, coaching, and referrals to home and community-based services.

#### Possible Implementation Actions

1. Evaluate other state models of including family caregiver assessments and supports in MLTSS such as TennCare CHOICES, Healthy Connections Prime (South Carolina), UnitedHealthcare, CalDuals Alzheimer's (California) for possible replication in Commonwealth.
2. Discuss with DMAS the feasibility of amending the CCC Plus MCO contracts to include family caregiver assessments and supports.
3. Meet with the Virginia Association of Health Plans, to discuss the feasibility of Medicaid MCO contractors including family caregiver assessments and supports.

One potential area for improvement affecting family caregivers in Virginia is coverage of home health services through telehealth. A recent state report card from the American Telemedicine Association gave Virginia an F on this measure.

UPDATE: DARS met with DMAS to discuss the feasibility of encouraging the inclusion of a caregiver assessment in the CCC Plus MCO contracts.

## Recognize ♦ Support ♦ Transform

**Recommendation 6:** Expand telehealth through broader Medicaid coverage of remote patient monitoring and coverage of telehealth services through the home health benefit, including a wide range of services and providers such as skilled nursing, physical therapy, behavioral health services, occupational therapy, or speech therapy visits.

### Possible Implementation Actions

1. Discuss the feasibility of expanding Medicaid coverage for telehealth services through the home health benefit.
2. If this is feasible, develop a budget request to expand telehealth services through the home health benefit.
3. Include reimbursement for telehealth services through the home health benefit.

### **DEPARTMENT OF HEALTH PROFESSIONS (DHP)**

---

**Action: DARS will meet with Board of Health Professions on ways to encourage family-centered care by the health and long-term services and supports workforce.**

**Recommendation 3:** The Virginia Family Caregiver Stakeholder Workgroup should present its findings on family caregivers and the need to train all providers on recognizing and engaging family caregivers to the Virginia Board of Health Professions to encourage family-centered care by the health and long-term services and supports workforce.

### Possible Implementation Actions

1. Virginia Family Caregiver Stakeholder Workgroup members will meet with Board of Health Professions.
2. Provide family-centered care information for inclusion in health board newsletters and board meeting packets.
3. Continue work with health professions boards on family caregiver and related cultural competencies as part of continuing education.

UPDATE: The Virginia Family Caregiver Stakeholder Workgroup members presented to the Virginia Board of Health Professions on August 23, 2018 recognizing family caregivers and began the discussion of family-centered care by the health and long-term services and supports workforce.

### **DEPARTMENT OF SOCIAL SERVICES (DSS)**

---

**Action: DARS will meet with DSS and Office on Volunteerism and Community Services to discuss home-based care (HBC) funding and respite volunteer programs.**

HBC often prevents vulnerable adults from descending into self-neglecting situations by helping these adults meet basic needs such as cooking meals, bathing, or minor house repairs, thus relieving the burden on family caregivers

## Recognize ♦ Support ♦ Transform

**Recommendation 4:** Amend the DSS budget to restore approximately \$3 million in funding to return funding for HBC to SFY 2009 (\$8,087,504) levels. Currently, the HBC allocation is \$5,536,481.

### Possible Implementation Actions

1. Discuss the feasibility of restoring HBC funding to its SFY 2009 levels (\$8,087,504).
2. If this is feasible, develop a budget request to restore HBC funding to its SFY 2009 levels (\$8,087,504).

**Recommendation 7:** Amend DARS budget \$100,000 annually to continue the pilot for the DARS Lifespan Respite Voucher Program. Additionally, Virginia should promote volunteer respite care programs through university and community college academic programs and faith-based and nonprofit organizations.

### Possible Implementation Actions

1. DARS propose budget request to restore \$100,000 to fund DARS Lifespan Respite Voucher Program.
2. DARS and DSS Office on Volunteerism and Community Services launch public awareness campaign to promote volunteer respite care programs
3. Obtain Lifespan Respite funding through the Administration for Community Living.

UPDATE: DARS has received notice of award of funding for the DARS Lifespan Respite Voucher Program from the Administration for Community Living.

### **DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES (DARS)**

**Recommendation 5:** A family caregiver tax credit could help working family caregivers pay for home care, adult day care, respite care, home modifications, equipment, or other supports that assist their loved ones and make it easier for the caregivers to work. By supporting family caregivers through a tax credit, Virginia can help people stay at home where they want to be, helping to delay or prevent more costly nursing home care, preventing avoidable hospitalizations, and saving taxpayer dollars.

### Possible Implementation Action:

1. Working with the VCC and potential stakeholders from the Virginia Employment Commission, the Virginia Department of Taxation and the Department of Human Resources Management, DARS will explore facilitating a *Family Caregiver in the Workforce Summit* to discuss paid family medical leave and other workplace policies, benefits, and programs to support family caregivers in the workforce.

**Recommendation 8:** Encourage statewide support for and promote VirginiaNavigator through state agencies adding a direct link to VirginiaNavigator on their agency websites, offering family caregivers easy access to a comprehensive self-directed tool for family caregiving information.

## Recognize ♦ Support ♦ Transform

### Possible Implementation Action

1. Promote state agencies adding a link to VirginiaNavigator through the Virginia Four Year Plan for Aging Services Process.

**Recommendation 9:** Encourage utilization of No Wrong Door’s online self-directed caregiver tool to find home and community-based services for care recipients. Such a tool enables caregivers to develop individual profiles easing access to service delivery.

**Recommendation 10:** Recognize through a press release the three winning teams of the annual Lindsay Institute for Innovations in Caregiving’s “Caring for the Caregiver” Hack to widely tout this one-of-a-kind, award-winning event in the Commonwealth, promote the technology innovations for caregivers created, and increase awareness of the family caregiving technology market for Virginia entrepreneurs and technology companies.

### Possible Implementation Actions

1. The Lindsay Institute for Innovations in Caregiving’s 4th Annual “Caring for the Caregiver Hack” will take place the weekend of October 26-28, 2018 at Troutman Sanders, LLC in downtown Richmond, Virginia. DARS will draft a press release and post social media coverage to recognize this year’s winners.
2. Provide press releases and social media coverage to promote examples of unique innovations in caregiving statewide.

**Recommendation 11:** Formulate a plan for private employers in the Commonwealth with 50 or more salaried employees to offer paid family medical leave for their employees who are family caregivers.

### Possible Implementation Action:

1. Working with the VCC and potential stakeholders from the Virginia Employment Commission, the Virginia Department of Taxation and the Department of Human Resources Management, DARS will explore facilitating a *Family Caregiver in the Workforce Summit* to discuss paid family medical leave and other workplace policies, benefits, and programs to support family caregivers in the workforce.

**Recommendation 12:** Institute a public awareness campaign to support the development and implementation of workplace policies, benefits, and programs to support family caregivers in the Commonwealth. In addition to family medical leave, this includes a caregiver resource list, support groups, in-house stress-reduction programs, subsidized back-up home care, and legal and financial counseling for employees and parents.

### Possible Implementation Action:

1. Working with the VCC and potential stakeholders from the Virginia Employment Commission, the Virginia Department of Taxation and the Department of Human Resources

## Recognize ♦ Support ♦ Transform

Management, DARS will explore facilitating a *Family Caregiver in the Workforce Summit* to discuss paid family medical leave and other workplace policies, benefits, and programs to support family caregivers in the workforce.

**Recommendation 13:** Develop and implement policies and procedures for benefits and programs in addition to leave policies to enable state employees who are family caregivers to be able to continue working while having sufficient time to care for aging or chronically ill family members.

Possible Implementation Action:

1. Working with the VCC and potential stakeholders from the Virginia Employment Commission, the Virginia Department of Taxation and the Department of Human Resources Management, DARS will explore facilitating a *Family Caregiver in the Workforce Summit* to discuss paid family medical leave and other workplace policies, benefits, and programs to support family caregivers in the workforce.

**Recommendation 15:** DARS will collaborate with the Virginia Caregiver Coalition to bring in speakers, do outreach, hold caregiver summits, and continue the development of the Virginia Family Caregiver Solution Center to house educational presentations.

Possible Implementation Action

1. Engaging internal and external resources, DARS will work with the VCC to identify and attain educational speakers and conduct outreach that recognizes and supports family caregivers.



# Recognize ♦ Support ♦ Transform

## EXECUTIVE SUMMARY

The Department for Aging and Rehabilitative Services (DARS) convened the Virginia Family Caregiver Stakeholder Workgroup in July 2017 in response to requests from legislators and advocates to study and develop ways for the Commonwealth to encourage and support families and communities in assisting aging adults and individuals with disabilities. This call to action responds to two critical data sets on family caregiving in Virginia. In 2015, the Virginia Department of Health's [Behavioral Risk Factor Surveillance System](#) (BRFSS) survey revealed one in five Virginians (20.7%) provided care or assistance in the past month to a friend or family member who was living with a health problem or disability. On June 14, 2017, AARP released *The Long-Term Services and Supports (LTSS) State Scorecard* ([www.longtermscorecard.org](http://www.longtermscorecard.org)). Although ranked 22<sup>nd</sup> overall on this scorecard, Virginia ranked an abysmal 47<sup>th</sup> in Support for Family Caregivers.

The term family caregiver means an adult family member or other individual who has a significant relationship with and who provides a broad range of assistance to an individual with a chronic or other health condition, disability, or functional limitation. This definition is used in the federal bipartisan Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act of 2017 that became Public Law 115-119 on January 22, 2018. The RAISE Family Caregivers Act requires the U.S. Secretary of Health and Human Services to develop, maintain, and update an integrated national strategy to support family caregivers. The goals of the strategy include identifying actions that government, communities, health providers, employers, and others can take to support family caregivers, including:

- Promoting adoption of person-centered and family-centered care in health and long-term care settings,
- Training for family caregivers,
- Respite options for family caregivers,
- Ways to increase financial security for family caregivers,
- Workplace policies to help family caregivers keep working, and
- Collecting and sharing information about innovative family caregiving models.

At the first meeting on July 27, 2017 of the Virginia Family Caregiver Stakeholder Workgroup, members discussed the pending RAISE Family Caregivers Act and its goals and were asked to provide individual recommendations for developing innovative means of providing support to Virginia family caregivers. The Workgroup convened again on November 17, 2017 to discuss the group's initial recommendations that aligned with many of the goals set forth in the RAISE Family Caregivers Act. Over the ensuing months, fifteen recommendations were compiled into an exposure draft that was made available on VirginiaNavigator for public comment in April 2018. This report provides fifteen recommendations to the Governor and General Assembly, state agencies, communities, health care and LTSS providers, employers, and others to support family caregivers.

## Recognize ♦ Support ♦ Transform

**Recommendation 1:** The Virginia Department of Health (VDH) should work to ensure Caregiver Advise, Record, and Enable (CARE) Act protections are realized through regulatory measures. The 2015 CARE Act in Virginia (Virginia Code § 32.1-137.03) requirements include giving the patient an opportunity to designate a caregiver and for the hospital to contact the designated caregiver, notify him or her of the hospital discharge and the discharge plan, and offer the caregiver instruction in aftercare tasks. VDH regulations should require collection of data by hospitals to track implementation and be amended to require that health systems include the family caregiver designation in their electronic medical records.

**Recommendation 2:** The Department of Medical Assistance Services (DMAS) and Managed Care Organization (MCO) health plans should amend Virginia's Commonwealth Coordinated Care Plus MCO contracts for Managed Long-Term Services and Supports to include a comprehensive assessment of the caregiver's health, well-being, and needs. The appropriate supports then should be provided to caregivers by the MCO care coordinators, for example, training, education, coaching, and referrals to home and community-based services.

**Recommendation 3:** The Virginia Family Caregiver Stakeholder Workgroup should present its findings on family caregivers and the need to train all providers on recognizing and engaging family caregivers to the Virginia Board of Health Professions to encourage family-centered care by the health and long-term services and supports workforce.

**Recommendation 4:** The Governor should introduce and the General Assembly should enact a budget amendment for the Virginia Department of Social Services (DSS) to restore approximately \$3 million in funding to return funding for home-based care (HBC) to SFY 2009 (\$8,087,504) levels. Currently, the HBC allocation is \$5,536,481. HBC often prevents vulnerable adults from descending into self-neglecting situations by helping these adults meet basic needs such as cooking meals, bathing, or minor house repairs, thus relieving the burden on family caregivers.

**Recommendation 5:** A family caregiver tax credit could help working family caregivers pay for home care, adult day care, respite care, home modifications, equipment, or other supports that assist their loved ones and make it easier for the caregivers to work. By supporting family caregivers through a tax credit, Virginia can help people stay at home where they want to be, helping to delay or prevent more costly nursing home care, preventing avoidable hospitalizations, and saving taxpayer dollars.

**Recommendation 6:** DMAS should expand telehealth through broader Medicaid coverage of remote patient monitoring and coverage of telehealth services through the home health benefit, including a wide range of services and providers such as skilled nursing, physical therapy, behavioral health services, occupational therapy, or speech therapy visits.

**Recommendation 7:** The Governor should introduce and the General Assembly should enact a budget amendment for \$100,000 annually to continue the pilot for the DARS Lifespan Respite Voucher Program. Additionally, Virginia should promote volunteer respite care programs through university and community college academic programs and faith-based and nonprofit organizations.

## Recognize ♦ Support ♦ Transform

**Recommendation 8:** The Governor should strengthen statewide support for and promote VirginiaNavigator by encouraging all state agencies to add a direct link to VirginiaNavigator on their agency websites, offering family caregivers easy access to a comprehensive self-directed tool for family caregiving information.

**Recommendation 9:** Encourage utilization of No Wrong Door’s online self-directed caregiver tool to find home and community-based services for care recipients. Such a tool enables caregivers to develop individual profiles easing access to service delivery.

**Recommendation 10:** The Governor’s Office should provide recognition each year to the three winning teams of the Lindsay Institute for Innovations in Caregiving’s “Caring for the Caregiver” Hack to widely tout this one-of-a-kind, award-winning event in the Commonwealth, promote the technology innovations for caregivers created, and increase awareness of the family caregiving technology market for Virginia entrepreneurs and technology companies.

**Recommendation 11:** The Virginia Employment Commission should develop a plan for a program for private employers in the Commonwealth with 50 or more salaried employees to offer paid family medical leave for their employees who are family caregivers.

**Recommendation 12:** The Secretary of Commerce and Trade and the Secretary of Health and Human Resources should embark on a public awareness campaign to support the development and implementation of workplace policies, benefits, and programs to support family caregivers in the Commonwealth. In addition to family medical leave, this includes a caregiver resource list, support groups, in-house stress-reduction programs, subsidized back-up home care, and legal and financial counseling for employees and parents.

**Recommendation 13:** The Secretary of Administration should direct the Department of Human Resources Management to develop and implement policies and procedures for benefits and programs in addition to leave policies to enable state employees who are family caregivers to be able to continue working while having sufficient time to care for aging or chronically ill family members.

**Recommendation 14:** The Secretary of Health and Human Resources should direct VDH to include the optional Caregiver Module questions in the Behavioral Risk Factor Surveillance System for 2019. This will cost VDH \$ 27,000 (9 questions x \$3000 per question=\$27,000) and a similar amount every three years thereafter for the collection of the optional Caregiver Module.

**Recommendation 15:** The Governor should introduce and the General Assembly should enact a budget amendment in the amount of \$30,000 to provide DARS funding to allow the Virginia Caregiver Coalition (VCC) to bring in speakers, do outreach, hold caregiver summits, and continue the development of the Virginia Family Caregiver Solution Center to house educational presentations.

# Recognize ♦ Support ♦ Transform

## FINDINGS

On June 14, 2017, AARP released *The Long-Term Services and Supports (LTSS) State Scorecard* ([www.longtermscorecard.org](http://www.longtermscorecard.org)). This compilation of state data and analysis showcases measures of state performance for creating a high-quality system of care to improve services for older adults and people with physical disabilities and their family caregivers. Although ranked 22nd overall on this scorecard, Virginia ranked an abysmal 47<sup>th</sup> in Support for Family Caregivers.<sup>1</sup>

The term family caregiver means an adult family member or other individual who has a significant relationship with and who provides a broad range of assistance to an individual with a chronic or other health condition, disability, or functional limitation. This definition is used in the federal bipartisan Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act of 2017 that became Public Law 115-119 on January 22, 2018. The RAISE Family Caregivers Act requires the U.S. Secretary of Health and Human Services to develop, maintain, and update an integrated national strategy to support family caregivers. The goals of the strategy include identifying actions that government, communities, health providers, employers, and others can take to support family caregivers, including:

- Promoting adoption of person-centered and family-centered care in health and long-term care settings,
- Training for family caregivers,
- Respite options for family caregivers,
- Ways to increase financial security for family caregivers,
- Workplace policies to help family caregivers keep working, and
- Collecting and sharing information about innovative family caregiving models.

According to *Families Caring for an Aging America*, the 2016 landmark study by the National Academies of Sciences, Engineering, and Medicine, family caregiving affects millions of Americans every day and yet the need to recognize and support family caregivers is among the most overlooked challenges facing us today. For decades, health and economic experts have called attention to the nation's rapidly aging population, especially the increasing numbers of

---

<sup>1</sup> The following indicators were used to gauge support for family caregivers: supports for working caregivers, person-and family-centered care, nurse delegation and scope of practice, and transportation policies

## Recognize ♦ Support ♦ Transform

chronically frail elderly, yet little has been done to prepare for the gap between the projected demand for caregivers and the population able to serve as caregivers. Developing programs and services that are accessible, affordable, and tailored to the needs of diverse communities of family caregivers also presents significant challenges. While the need for caregiving is increasing, the pool of potential family caregivers is shrinking as families have fewer children, older adults are more likely to have never married or to be widowed or divorced, and adult children live far from parents or may be caring for more than one older adult or their own children.<sup>2</sup> In 2013, 1,030,000 family caregivers in Virginia (about 12.5% of the state's population) provided an estimated 956 *million* hours of care to loved ones. The estimated economic value of their unpaid contributions was approximately \$11.8 billion in 2013 (Table A). This estimate is conservative because it does not factor in the physical, emotional, and financial costs of care.

Just two years later, the Virginia Department of Health included the Caregiver module in their 2015 [Behavioral Risk Factor Surveillance System](#) (BRFSS) survey. According to the BRFSS survey, one in *five* Virginians (20.7%) provided care or assistance in the past month to a friend or family member who was living with a health problem or disability. For 35% of caregivers, the care recipient was a parent and for 13.1% a spouse. Almost a third (31.5%) had been providing care for *more than 5 years*. Over half of the caregivers (55.7%) provided up to eight hours of care per week and 17.6% provided 40 hours of care or more. Approximately 16% of caregivers anticipated continuing to provide care over the next two years. When asked about support services they need most but are not receiving, 10.3% of caregivers said they are not getting help accessing services and 8.2% said they do not have access to classes about providing care, support groups, counseling, or respite care. Eighty percent of caregivers were managing household tasks for their care recipient. Finally, 52.3% were managing the personal care of the care recipient.

Caregivers are more likely to report worsening health and experiencing caregiver burnout if they care for someone with a mental health issue, are higher-hour caregivers, care for a close relative, live with the care recipient, do medical or nursing tasks, or are the primary caregiver. Physical strain, financial problems, and emotional stress are more common among higher-hour caregivers and caregivers who feel they had no choice in their caregiving role. These caregivers are

---

<sup>2</sup> National Academies of Sciences, Engineering, and Medicine. 2016. Families Caring for an Aging America. Washington, DC: The National Academies Press. <https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america>, p.2.

# Recognize ♦ Support ♦ Transform

**Table A** Number of Family Caregivers and the Economic Value of Caregiving by State, 2013

State	State Population	Number of Caregivers	Number of Care Hours (millions)	Economic Value per Hour	Total Economic Value (millions)
Alabama	4,830,000	761,000	708	\$10.89	\$7,720
Alaska	735,000	84,900	79	\$15.05	\$1,190
Arizona	6,630,000	804,000	749	\$12.60	\$9,430
Arkansas	2,960,000	452,000	421	\$11.20	\$4,710
California	38,300,000	4,450,000	4,140	\$13.94	\$57,700
Colorado	5,270,000	584,000	543	\$13.66	\$7,430
Connecticut	3,600,000	459,000	427	\$13.87	\$5,930
Delaware	926,000	123,000	114	\$13.86	\$1,580
District of Columbia	646,000	75,200	70	\$12.44	\$870
Florida	19,600,000	2,670,000	2,490	\$11.93	\$29,700
Georgia	9,990,000	1,330,000	1,240	\$11.29	\$14,000
Hawaii	1,400,000	154,000	144	\$14.59	\$2,100
Idaho	1,610,000	196,000	183	\$12.06	\$2,210
Illinois	12,900,000	1,560,000	1,450	\$12.77	\$18,500
Indiana	6,570,000	837,000	779	\$12.17	\$9,480
Iowa	3,090,000	317,000	295	\$13.08	\$3,860
Kansas	2,890,000	345,000	321	\$12.01	\$3,850
Kentucky	4,400,000	648,000	603	\$11.57	\$6,980
Louisiana	4,630,000	660,000	615	\$10.53	\$6,470
Maine	1,330,000	178,000	165	\$13.41	\$2,220
Maryland	5,930,000	771,000	717	\$13.09	\$9,390
Massachusetts	6,690,000	844,000	786	\$14.75	\$11,600
Michigan	9,900,000	1,280,000	1,190	\$12.21	\$14,500
Minnesota	5,420,000	585,000	544	\$14.45	\$7,860
Mississippi	2,990,000	501,000	467	\$11.53	\$5,380
Missouri	6,040,000	792,000	737	\$11.52	\$8,490
Montana	1,020,000	118,000	110	\$12.97	\$1,430
Nebraska	1,870,000	195,000	182	\$13.81	\$2,510
Nevada	2,790,000	348,000	324	\$13.19	\$4,270
New Hampshire	1,320,000	173,000	161	\$14.42	\$2,330
New Jersey	8,900,000	1,120,000	1,040	\$13.07	\$13,600
New Mexico	2,090,000	277,000	257	\$12.19	\$3,140
New York	19,700,000	2,580,000	2,400	\$13.02	\$31,300
North Carolina	9,850,000	1,280,000	1,190	\$11.27	\$13,400
North Dakota	723,000	62,100	58	\$14.88	\$860
Ohio	11,600,000	1,480,000	1,380	\$11.95	\$16,500
Oklahoma	3,850,000	524,000	488	\$12.45	\$6,070
Oregon	3,930,000	469,000	437	\$13.06	\$5,700
Pennsylvania	12,800,000	1,650,000	1,540	\$12.47	\$19,200
Rhode Island	1,050,000	134,000	124	\$14.26	\$1,780
South Carolina	4,770,000	706,000	657	\$11.49	\$7,550
South Dakota	845,000	84,600	79	\$13.12	\$1,030
Tennessee	6,500,000	981,000	913	\$11.24	\$10,300
Texas	26,400,000	3,350,000	3,120	\$11.39	\$35,500
Utah	2,900,000	336,000	313	\$13.26	\$4,150
Vermont	627,000	71,900	70	\$14.55	\$1,010
Virginia	8,260,000	1,030,000	956	\$12.36	\$11,800
Washington	6,970,000	828,000	771	\$13.83	\$10,700
West Virginia	1,850,000	282,000	263	\$10.62	\$2,790
Wisconsin	5,740,000	578,000	538	\$13.15	\$7,070
Wyoming	583,000	66,200	62	\$13.27	\$817
<b>United States</b>	<b>316,000,000</b>	<b>40,000,000</b>	<b>37,000</b>	<b>\$12.51</b>	<b>\$470,000</b>

Note: State numbers may not add up exactly to the U.S. totals because of rounding.

Adapted from: Reinhard, S., Feinburg, L., R., & Houser, A. (2015), Valuing the Invaluable: 2015 Update, Insight on the Issues, 104 (July 2015), 22-25.

## Recognize ♦ Support ♦ Transform

vulnerable due to their levels of burden and are in need of support. Caregivers require a break from their caregiving responsibilities to address their own needs, but without access to respite and stress reduction strategies, caregivers are challenged to find the time and tools to perform vital self-care. The absence of self-care places the caregiver’s ability to provide care at risk. *Families Caring for an Aging America*, p. 5.

In “Home Alone: Family Caregivers Providing Complex Chronic Care,” published in 2012, AARP reported that 46% of family caregivers were performing medical or nursing tasks for care recipients with multiple, chronic physical and cognitive conditions<sup>3</sup>. Despite the expanding and increasingly complex assistance provided by family caregivers, they are an invisible workforce performing tasks that would otherwise require costly government nursing home placement or community-based care. Further, Medicare and other payers’ financial incentives encourage shorter hospital stays with the expectation that family members can support home care and manage the transition from the hospital. Providers expect family caregivers—with little or no training—to handle technical procedures and equipment for older adults at home, such as feeding and drainage tubes, catheters, and tracheotomies, and to manage and monitor their condition. Family caregivers describe learning by trial and error and fearing that they will make a life-threatening mistake. Despite the integral role that family caregivers play in the care of older adults with disabilities and complex health needs, caregivers are often marginalized in the delivery of health care and LTSS and are often ignored in public policy development and implementation too. *Families Caring for an Aging America*, 2016, p. 4.

The following public and private sector policies are recommended by the Family Caregiver Stakeholder Workgroup to support the capacity of family caregivers to perform critical caregiving tasks and respond to the goals of the federal RAISE Family Caregivers Act of 2017.

### RECOMMENDATIONS

**GOAL I: FAMILY CENTERED CARE** Today’s emphasis on person-centered care in facilities and formal care settings needs to evolve into a focus on person-centered and family-centered care in communities across the Commonwealth. Ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports to their care recipients.

<sup>3</sup> S.C. Reinhard, C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute, and New York: United Hospital Fund, October 2012). Accessed at: [https://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf](https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf)

# Recognize ♦ Support ♦ Transform

## Background

The 2015 CARE Act in Virginia (Virginia Code §32.1-137.03) outlines statutory requirements guiding the family caregiver and hospital upon discharge of a patient from an inpatient hospital stay. These requirements include giving the patient an opportunity to designate a caregiver and for the hospital to contact the designated caregiver to notify him or her of hospital discharge date and plan, and offer caregiver instruction in aftercare tasks. What is less clear to family caregiver advocates are the types of education and awareness campaigns that have been developed and delivered to Virginia's hospitals by VDH regarding their role in the CARE Act implementation.

The Commonwealth needs to work to ensure CARE Act protections are realized through regulatory measures. The Commonwealth should collect data from hospitals to track implementation, and continue a robust education and oversight effort going forward as the law's requirements are adopted into hospital practice. Regulations should be amended to require that health systems include the family caregiver designation in their patient's electronic medical record (EMR). Most EMRs identify the next of kin and health care power of attorney, but many do not specifically identify the family caregiver who will be managing the patient's care after a doctor's appointment, emergency department (ED) visit, or inpatient stay. Having the family caregiver designation in the EMR will allow for a better understanding at the health system level and within various settings (e.g., inpatient hospital, acute care, primary care) of the number of patients reporting a family member or friend who assists them with their care needs. Those hospitals or health systems that are tracking family caregivers are mostly doing so at discharge when they use their definition of a caregiver and inquire "do you need assistance at home, with obtaining prescriptions, with transportation to medical appointments, etc.?" If the response is "yes," they are asked to identify this person. There are also opportunities to track the caregiver upon the patient's admission to the ED or hospital and for the care management team to verify, monitor, and update this information as needed. Not only would this tracking in the EMR allow hospitals to comply with the CARE Act, but it could be taken a step further to have caregivers self-identify this role to be recorded in their own EMR. This would allow treating physicians an opportunity to better understand the potential strain, challenges, and rewards their patients may be experiencing as a caregiver. Both types of recording and identification of the caregiver, for the patient who has a caregiver and for the patient who is a caregiver, will involve some training and education for health system staff in determining who that caregiver may be and most importantly, how to assist him or her in that critical role. This will also move health systems



## Recognize ♦ Support ♦ Transform

towards true integration of the family caregiver as a member of the health care team. Healthcare systems cannot manage the care of older adults adequately without family caregivers.

### **Recommendation 1**

VDH should work to ensure CARE Act protections are realized through regulatory measures. VDH regulations should require collection of data by hospitals to track implementation and be amended to require that health systems include the family caregiver designation in their patient's EMR.

**GOAL II: ENGAGE FAMILY CAREGIVERS IN CARE** Implement provider payment reforms that motivate providers to engage family caregivers in delivery processes across payment methods and models of care. Assessing and addressing family caregivers' unmet needs for education, information, and supportive services should be standard practice in all home and community-based service programs that aim to help beneficiaries remain at home and in the community. In Medicaid, many states formally or informally assess family caregivers as part of the process for developing long term services and supports care plans.

### Background

As Virginia shifts to Managed Long Term Services and Supports (MLTSS), a key component must not be left out of the equation: family caregivers. The Commonwealth Coordinated Care (CCC) Plus Managed Care Organizations (MCO) Contract for MLTSS briefly mentions caregivers, but this is limited to the provision of respite care for primary unpaid caregivers, identifies them as a source of information for the beneficiary's health risk assessment, and designates them as a potential member of the beneficiary's interdisciplinary care team.<sup>4</sup> A report released by the AARP Public Policy Institute in November 2016 emphasizes that caregivers are an invaluable part of the care team and often make the difference between a beneficiary remaining in the community or being institutionalized.

<sup>4</sup> [http://www.dmas.virginia.gov/Content\\_atchs/mltss/Final%20CCC%20Plus%20Contract%20-%20revised%20%20June%2009.pdf](http://www.dmas.virginia.gov/Content_atchs/mltss/Final%20CCC%20Plus%20Contract%20-%20revised%20%20June%2009.pdf)

### **A Regular Monthly Call with a Caregiver**

*Having lost 25 pounds in 6 weeks, suffering several falls and overall diminished functional status, one of JABA's dementia clients needed immediate attention and resources. The client's greatest asset was her son and caregiver who shared with the care coordinator (CC) details of his mother's decline. He explained his mother's harrowing daily trip upstairs to reach her bedroom and shower without the benefit of handrails to hold, only someone behind her to catch her if she fell. He was very concerned for his mother.*

*Working with the Memory and Aging Care Clinic, UVA, community organizations and donors the CC at JABA was able to get an appointment with the Memory Clinic, secure a cane, walker and other durable medical equipment to assist with client's mobility, and a chair lift to conquer the stairs.*

*The caregiver was speechless with everything the CC was able to provide. It was a game changer for JABA's client and reduced the stress and concerns of the caregiver. Assessing the caregiver and client proved beneficial to the client and the caregiver's well-being.*

## Recognize ♦ Support ♦ Transform

Research has found that high caregiver stress is a predictor of placement in a nursing home of a care recipient. Caregivers experience stress due to emotional, physical, and financial responsibilities required of them, and without proper support they will burnout, potentially leaving their loved one without a care provider, which can lead to institutionalization. The care they provide in the community, including personal and often medical care, is invaluable. Caregivers are at risk of becoming patients themselves and should be supported by MCOs to help them stay healthy.<sup>5</sup>

### **Recommendation 2**

DMAS and the MCO health plans should amend Virginia's CCC Plus MCO contracts for MLTSS to include a comprehensive assessment of the caregiver's health, well-being, and needs and require the appropriate supports then be provided to caregivers, for example training, education, coaching, and referrals to home and community-based services. AARP cites best practices from other states including Tennessee, South Carolina, California and managed care organizations including UnitedHealthcare that Virginia can emulate.<sup>6</sup> (Appendix A) Recognizing that the health and well-being of beneficiaries and their caregivers are closely linked, an effective assessment must include both. The assessment is an opportunity to ask caregivers how they are doing and determine what information and assistance they need. This model of assessing both the patient and the caregiver is being successfully piloted by the University of Virginia Memory and Aging Care Clinic and the Jefferson Area Board for Aging (JABA) as they implement a Care Coordination Program for individuals diagnosed with dementia. The Department for Aging and Rehabilitative Services (DARS) is providing funding and leadership.

In this program, patients and their caregivers receive an initial in-home assessment and are re-assessed at every additional encounter, which at minimum includes a monthly phone call. They have a care coordinator who is available to address their needs together or individually. Experts frequently cite caregivers as the backbone of our long-term care system. Virginia must not leave supporting them out of the equation as the Commonwealth transitions to MLTSS for Medicaid recipients and other populations.

**GOAL III: TRAINING AND CAPACITY** Strengthen the training and capacity of health care and social services providers to recognize and engage family caregivers and to provide caregivers evidence-based supports and referrals to services in the community.

<sup>5</sup> [http://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080\\_FSandMLTSS\\_REPORT\\_WEB.pdf](http://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080_FSandMLTSS_REPORT_WEB.pdf)

<sup>6</sup> Ibid.

# Recognize ♦ Support ♦ Transform

## Caregiver Training and Experience Leads to Career

*“Judy,” the primary caregiver for her grandmother who was diagnosed with Alzheimer’s disease, was an active participant in the Family Caregiver Lunch and Learn Series at Peninsula Agency on Aging. The trainings provided answers to Judy’s questions and she encouraged others to participate. Being unable to attend college because of her caregiving duties, she was very interested in learning as much as possible about professional caregiving during the Lunch and Learns. She said the training she had received and the community resources she had learned about made her caregiving tasks much more manageable. After her grandmother’s passing, she completed the CNA program and now works as a CNA for a local home health agency where her years of caregiving experience now serve others.*

## Background

To ensure both person- and family-centered care by the health and LTSS workforce, providers should treat family caregivers not just as a resource in the treatment or support of a patient, but also as partners and people who may themselves need information, training, care, and support. Providers are inclined to assume that the care provided by a caregiver will remain as a constant. In reality, caregivers often feel overwhelmed and under-supported which can lead to declines in their health and wellbeing and jeopardize or derail their ability to provide care. Engaging family caregivers requires that all types of providers be able to:

1. Recognize a family caregiver’s presence,
2. Assess whether and how the family caregiver can best participate in overall care,
3. Engage and share information with the family caregiver,
4. Help caregivers develop actual skills to provide care,
5. Recognize the family caregiver’s own health care and support needs, and
6. Help caregivers obtain needed support by referring family caregivers to appropriate services and follow up on their receipt and effectiveness of those services.

Given the growing diversity of the population and their family caregivers, cultural competence in exercising these skills is essential to their effectiveness. *Families Caring for an Aging America*, p. 10. Cultural competence in health care refers to the ability of healthcare professionals to provide optimal care to patients regardless of their race, gender, ethnic background, native languages spoken, and religious or cultural beliefs.

### **Recommendation 3**

The Virginia Family Caregiver Stakeholder Workgroup should present its findings on family caregivers and the need to train all providers on recognizing and engaging family caregivers to the Virginia Board of

## Recognize ♦ Support ♦ Transform

Health Professions to encourage family-centered care by the health and LTSS workforce. The Virginia Board of Health Professions is an 18-member board with representatives from each of the 13 health regulatory boards and five citizen members from across the state. One of the chief responsibilities of the board is to advise the Department of Health Professions Director, the Secretary of Health and Human Resources, the Governor, and the General Assembly on matters relating to the regulation of health care providers.

Professional organizations in social work and nursing have led the way in taking steps to build a workforce with the competencies necessary for person- and family-centered care. Medical and social services providers need to provide education and referrals to family caregivers. All licensed health professions should be encouraged to identify specific competencies by provider type to demonstrate effective practices to include development of continuing education programs and curricula and training to instill those competencies. Cultural competence should be a core aspect of provider competencies in working with family caregivers.

### **Recommendation 4**

The Governor should introduce and The General Assembly should enact a budget amendment restoring approximately \$3 million in funding to DSS to return funding for home-based care (HBC) to SFY 2009 (\$8,087,504) levels. Social services funding for supportive HBC in the community, such as homemaker, chore, or companion services, has declined almost 32% from SFY 2009 to SFY 2018. Funds are used to pay providers hired by the local departments of social services (LDSS) or from home care agencies to help clients with activities of daily living such as bathing and dressing, instrumental activities of daily living such as housekeeping and meal preparation, or minor house repairs with the goal of keeping older adults and individuals with disabilities in their homes. Many older adults indicate that they wish to remain in their homes for as long as possible.<sup>7</sup> However, as funding has decreased and demand has increased, LDSS have been forced to reduce current HBC clients' hours, close less critical cases, and add clients to the waiting lists for services. This cut in funding has also increased burdens on family caregivers.

---

<sup>7</sup> AARP (2011). *Aging in place: a state survey of livability policies and practices*. Retrieved from <http://assets.aarp.org/rgcenter/ppi/liv-com/aging-in-place-2011-full.pdf>

# Recognize ♦ Support ♦ Transform

## Home-based Services Cases 2009-2018

Year	HBC Allocations
2009	\$8,087,504
2010	\$7,379,840
2011	\$6,051,469
2012	\$6,054,107
2013	\$6,054,107
2014-2018	\$5,536,481

When home-based services funding is not available, adults who still need assistance turn to family caregivers or more costly interventions, including assisted living or nursing home care. A 2011 analysis by the Department of Social Services Office of Research & Planning determined that eliminating the home-based services programs funded via the Social Services Block Grant would increase state general fund costs by an estimated \$6.6 million as adults sought more costly supports.<sup>8</sup> It is also important to note that home-based services often prevent vulnerable adults from descending into self-neglecting situations by helping these adults meet basic needs such as cooking meals, bathing, or minor house repairs thus relieving the burden on family caregivers.

**GOAL IV: CAREGIVER STATE INCOME TAX CREDIT** The General Assembly should enact a modest Caregiver State Income Tax Credit to give family caregivers relief when using their own money to care for a loved one.

### Background

Caregiving is costly in terms of direct expenses and potential income and retirement savings sacrificed. An AARP study found that nationally on average family caregivers spent \$6,954 out-of-pocket on caregiving expenses in 2016, or nearly 20% of their income on average.<sup>9</sup> Long-distance caregivers averaged \$11,923 in annual expenses.

### **Recommendation 5**

A family caregiver tax credit could help working family caregivers pay for home care, adult day care, respite care, home modifications, equipment, or other supports that assist their loved ones

<sup>8</sup> Results of analysis provided by DSS Office of Research & Planning via email to DSS Adult Protective Services staff, October 17, 2011.

<sup>9</sup> Rainville, Chuck, Laura Skufca, and Laura Mehegan. *Family Caregiving and Out-of-Pocket Costs: 2016 Report*. AARP Research, Washington, DC (November 2016).

## Recognize ♦ Support ♦ Transform

and make it easier for the caregivers to work. By supporting family caregivers through a tax credit, Virginia can help people stay at home where they want to be, helping to delay or prevent more costly nursing home care and preventing avoidable hospitalizations, and saving taxpayer dollars. There are many ways that Virginia could structure a family caregiver tax credit to help the family caregivers most in need and limit the financial impact on the state, for example, income eligibility criteria, maximum credit amount, qualified expenses or refundable designation. Across party lines, a strong majority (87%) of likely voters age 50 and older support a tax credit for working family caregivers according to an AARP poll conducted nationally in November 2016.<sup>10</sup> Virginia also has a history of financial support for caregivers, such as the Virginia Caregivers Grant Program that provided annual grants of up to \$500 to caregivers who provided unreimbursed care to a needy relative until that program was discontinued in 2008.<sup>11</sup>

**GOAL V: TELEHEALTH** Break down the barriers that prevent the use of telehealth and support digital information and communication technologies, like computers and mobile devices, that help family caregivers manage their own and their loved ones' health.

### Background

Telehealth holds the promise of multiple solutions to help people access health and home and community-based services (HCBS) in new ways and to make it easier for family caregivers to care for their loved ones. AARP has been engaged in many states to ensure that telehealth is broadly construed and is widely accessible and that unreasonable barriers to utilization are not placed on consumers. More and more AARP members, especially those aged 50-59 are using their computers, mobile devices, and tablets to access information about their health. The true potential of telehealth can only be realized when lawmakers and the health care industry consider the needs and preferences of these older consumers and especially family caregivers when they address telehealth in their states.

In particular, telehealth can help family caregivers in ways that are not often discussed.

- Telehealth can bring routine and specialty health services into the home when trips out of home are challenging.

<sup>10</sup> See AARP Press Room, *AARP Backs Bipartisan Credit for Caring Act* (May 18, 2017), available at: <https://press.aarp.org/2017-05-18-AARP-Backs-Bipartisan-Credit-for-Caring-Act>, (numbers based on internal polling).

<sup>11</sup> See Va. Code § 63.2-2200 et seq.

## Recognize ♦ Support ♦ Transform

- Working and long-distance family caregivers can virtually join their loved ones' medical visits and care plan meetings, so they can help manage their care.
- When family caregivers sacrifice their own health care to care for others, a telehealth visit for themselves can help them save time and still take care of their own – physical, mental, or emotional needs. For example, psychosocial therapy and support groups via telehealth technology can help family caregivers cope with the challenging behaviors related to dementia and their own response to them.
- Technologies like remote patient monitoring give family caregivers the peace of mind that professionals are also keeping track of the health status of their loved ones.
- Telehealth can be used to demonstrate skills needed by family caregivers such as safe transfers, use of equipment, and positioning to improve safety for caregivers and care recipients.
- Telehealth can be used for care conferences and coordination when individuals are served by multiple providers in varied settings.

### **Recommendation 6**

One potential area for improvement affecting family caregivers in Virginia is coverage of home health services through telehealth. A recent state report card from the American Telemedicine Association gave Virginia an F on this measure.<sup>12</sup> DMAS should expand telehealth through broader Medicaid coverage of remote patient monitoring and coverage of telehealth services through the home health benefit, including a wide range of services and providers such as skilled nursing, physical therapy, occupational therapy, behavioral health services or speech therapy visits.

**GOAL VI: RESPITE** Significantly increase services that allow family caregivers to take regular, planned, hard-earned breaks.

### Background

Caregiver fatigue can contribute to negative health outcomes, depression, isolation, exhaustion, feeling overwhelmed, and an increased use of medications. The decline of caregiver health is a key risk factor for the institutionalization and abuse or neglect of a care recipient. Respite is an

---

<sup>12</sup> Thomas, L. & Capistrant, G., *50 State Telemedicine Gaps Analysis: Coverage & Reimbursement*. American Telemedicine Association, Washington, DC (February 2017).

## Recognize ♦ Support ♦ Transform

invaluable resource for caregivers experiencing high levels of stress and burden associated with their caregiving duties. It provides primary family caregivers with reliable care options while they engage in self-care and tend to other family, social, and community roles that are needed to help maintain friendships, social activities, and balance in one's life. Respite care also functions to enrich a family's general wellbeing and stability, and health professionals on the front line of family care should understand both the impact of caregiver fatigue and resources to help caregivers relieve the stress of their caregiving duties.

Respite as defined by ARCH National Respite Network and Resource Center is, "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult."<sup>13</sup> Respite services may be provided by a skilled or unskilled care provider from an individual or organization on a temporary basis, in settings that include the family home, residential care facilities, adult day centers, and respite centers.

The U.S. Congress passed the Lifespan Respite Care Act of 2006 to expand respite care services for caregivers in every state. DARS had a Lifespan Respite Voucher Program funded through two federal grants from the U.S. Department of Health and Human Services Administration on Aging, Administration for Community Living (ACL) from 2011-2017.

DARS' Lifespan Respite Voucher Program provided reimbursement of up to \$400 per year per family for the primary family caregiver of an individual in need of respite services. This program was for the primary family caregiver who resided with a disabled family member. The disabled family member could be of any age with any disability. Funds through the program were used to provide services that allowed the caregiver to take a break from caregiving duties. The program was consumer-directed and the primary family caregiver was allowed to

<sup>13</sup> <https://archrespite.org/>

### Caregiver's Community Network

The network is a unique collaborative partnership between Valley Program for Aging Services and James Madison University's Institute for Innovation in Health and Human Services. It provides students with an experiential opportunity to engage with frail older adults and adults with dementia while providing a time of respite for the family caregiver.

*"I originally signed up for this class in hopes that it would offer my hectic, difficult schedule some relief. Little did I know the extent of this relief. The elder I visited made a huge impact on my life and on the way I will forever approach life. Our visits were not huge psychological analyses or in-depth discussions of the mysteries of human existence, but rather periods of quiet reflection and carrying out simple tasks. Yet these visits caused much introspection and clarity in my life. This experience not only solidified my decision to become a nurse, but it has instilled in me a new motivation and drive to get there. Thanks to my elder, I came to realize that life has a great amount to offer and that there is beauty even in the struggle to achieve such goals."*



## Recognize ♦ Support ♦ Transform

utilize skilled or unskilled care from formal or informal providers through an individual or agency in the family home, the home of a neighbor or friend, an adult day center, a respite center, or a group home.

### **Recommendation 7**

The Governor should introduce and the General Assembly should enact a budget amendment for \$100,000 annually to continue the pilot for the DARS Lifespan Respite Voucher Program. Additionally, Virginia should promote volunteer respite care programs through university, and community college academic programs and faith-based and nonprofit organizations.

**GOAL VII: INFORMATION AND REFERRAL** Bolster and promote existing statewide public-private resources that provide guidance and direction to caregivers, especially those that offer access to vital long-term services and supports.

### Background

Caregivers are increasingly going online in pursuit of information and support. A 2013 report by the Pew Research Center<sup>14</sup> indicates that 84% of caregivers with Internet access go online to access information about a particular treatment or disease, medications, or health insurance. A majority of those caregivers (59%) report that the Internet has been helpful to their ability to provide care and support.

VirginiaNavigator, a public-private partnership 501(c)(3) non-profit, provides free health and community support information and guidance to older adults, people with disabilities, and veterans and their caregivers and families through its one-of-a-kind family of websites and grassroots-based centers. Launched in 2001, the SeniorNavigator website focused exclusively on older adults and their family caregivers. With a strong public-private infrastructure and growing visitorship, SeniorNavigator has become VirginiaNavigator and expanded its offerings to additional populations with a special focus on the family caregiver, family advocate, and military/veterans caregiver. Now, through an award-winning family of websites ([disAbilityNavigator.org](http://disAbilityNavigator.org); [SeniorNavigator.org](http://SeniorNavigator.org); [VeteransNavigator.org](http://VeteransNavigator.org)) SeniorNavigator offers:

- An easy-to-search database of 26,000+ programs and services;

<sup>14</sup> <http://www.pewinternet.org/2013/06/20/family-caregivers-are-wired-for-health/>

## Recognize ♦ Support ♦ Transform

- 800+ articles aggregated from a wide-range of well-respected organizations educate and help guide consumers through often difficult transitions and decisions;
- 742 Navigator Centers developed through partnerships with senior centers, libraries, hospitals, police stations, and churches serve as community access points for all Virginians in every city and county;
- “Ask an Expert” provide free, confidential, expert assistance powered by 70 subject matter professionals including physicians, attorneys, health insurance experts, and benefits specialists who volunteer their time to provide comfort and answers; and
- A robust Virginia Family Caregiver Solution Center developed in partnership with the DARS and the Virginia Caregiver Coalition provides a wide variety of helpful tools to family caregivers with an emphasis on respite resources.

An innovative service model combining information technology with community building, VirginiaNavigator and its family of websites bring a high-tech/high-touch approach to healthy lifestyles and long-term services and supports. By combining 24/7 online assistance through the family of websites and personal help through the network of 742 community-based Navigator Centers, the VirginiaNavigator family of websites brought critical support resources to families over 1.5 million times in 2017 alone. With a vision of Virginians being educated and empowered to make the best-possible decisions, VirginiaNavigator provides an objective, comprehensive look at the options available to help families through a comprehensive vetted list of public, private, non-profit, for-profit, volunteer-led, and veterans service organizations.

With a vision of streamlining access to services and supports for older adults, individuals with disabilities, caregivers, and families, the federal Administration for Community Living (ACL) developed an initiative called No Wrong Door (NWD), formerly Aging and Disability Resource Centers. With a focus on community integration for individuals with disabilities to receive services in their home and community, the ACL and Centers for Medicare and Medicaid Services (CMS) came together in 2003, developing the idea for today’s national NWD initiative. NWD is a statewide public/private partnership between DARS and VirginiaNavigator that includes a comprehensive governance structure to ensure decisions made regarding policy, technology development, and resource allocations are based on a shared vision and benefit the public and private sectors. The NWD Resource Advisory Council consists of 39 members, representing HHR agencies, statewide networks of providers of long term services and supports, and self/family advocates that include caregivers.

## Recognize ♦ Support ♦ Transform

In addition to engaging family caregivers and providing them with information and referrals to services in their communities, VirginiaNavigator and NWD are designed to expand the capacity of state and local government by putting access to resources directly into consumers' hands.

### **Recommendation 8**

The Governor should strengthen statewide support for and promote VirginiaNavigator by encouraging all state agencies to add a direct link to VirginiaNavigator on their agency websites, offering family caregivers easy access to a comprehensive self-directed tool. This can come in the form of a simple URL link, logo link or “service finder” widget.

### **Recommendation 9**

Enhance utilization of NWD’s online self-directed caregiver tool to find home and community-based services for care recipients. Such a tool enables caregivers to develop individual profiles easing access to service delivery.

**GOAL VIII: TECHNOLOGY INNOVATION** Be a catalyst toward greater technology innovation in caregiving in Virginia by promoting existing efforts that educate young adults on the realities of caregiving and provide the opportunity for informed caregiver technology development. This will help raise awareness among Virginia entrepreneurs and Virginia-based technology companies of the business case around meeting the unique needs of a growing cohort of caregivers.

### Background

According to *Families Caring for an Aging America*, p. 14, a growing body of evidence indicates that technology can be effectively employed to help caregivers, indicating that technology-based caregiver support, education, and skills training may enhance caregiver and older adult outcomes.

The Lindsay Institute for Innovations in Caregiving (Lindsay Institute) was founded in 2014 to encourage collaboration in improving caregiver health. The Lindsay Institute is housed at VirginiaNavigator, an independent and collaborative public/private partnership non-profit with a well-utilized web platform and a unique network of 742 grassroots-based centers.

## Recognize ♦ Support ♦ Transform

---

### “Caring for the Caregiver” Hack

The Lindsay Institute for Innovations in Caregiving (Lindsay Institute)

*“Serving as a judge at the ‘Caring for the Caregiver Hack’ was an extraordinary opportunity to witness the diverse array of extraordinary talent and creativity among the student teams at the 7 participating colleges and universities... What especially struck me was the manner in which the teams grasped the everyday challenges of the Caregiver in a very personal way and sought to use their respective knowledge and technical acumen to develop tools that not only may offer real help but that are feasible, marketable, and scalable. I approached Sunday feeling like it might be a fun afternoon and left moved to tears by the empathy shown for what so many in healthcare neglect: the millions of everyday people who sacrifice themselves to make someone else’s day just a little bit better... based on the talent on display at the “Caring for the Caregiver Hack,” the future of health care technology is very, very bright.”*

*-Patrick J. Hurd  
Partner/Attorney at Law  
LeClairRyan*

---

The mission of the Lindsay Institute is to preserve and improve the health of family and paid caregivers with a special focus on caregivers of individuals with dementia and other serious chronic diseases. The Lindsay Institute’s priority moving forward is education of caregivers and professionals and the development of caregiver technology using tech developers, disseminators of information on tech tools, and consultants to tech developers.

The backbone of the Lindsay Institute is its Advisory Council, which has fostered exciting and unparalleled opportunities for interdisciplinary collaboration, partnerships, and innovation development focused on improving the health of caregivers. The Advisory Council is comprised of 28 leaders representing technology, academia, gerontology, Alzheimer’s/related dementia-focused organizations, social work, nursing, occupational therapy, public health, and disability and caregiving services. The strong tie to Virginia’s academic centers through Advisory Council participation allows the Lindsay Institute to cultivate and create evidence-based programs like an annual hack competition started in 2015.

The Lindsay Institute has hosted three intergenerational “Caring for the Caregiver” Hack challenges, with teams from seven Virginia Colleges and Universities (UVA, VCU, VT, W&M, GMU, JMU and Lynchburg College) being matched with caregivers. Over a 24-hour period, they work to develop tech-based tools benefitting family caregivers with friendly competition to pitch the best idea with the most potential to a panel of expert judges. Students learn first-hand about growing aging and caregiver populations, the serious challenges around caregiver health, and why the time is right to leverage technology. In a post-event survey, 97% of students and 100% of faculty coaches said the hack experience met or exceeded their expectations, and 87% of students and 100% of faculty planned to incorporate what they learned in their current or future roles as a student or professional.

## Recognize ♦ Support ♦ Transform

### **Caregivers in the Workplace**

*Riverside Center for Excellence in Aging and Lifelong Health led a team to address double duty caregivers, those healthcare team members who also care for adults or older adults at home. Their project resulted in the implementation of an AIR (Affirmation, Information, Restoration) Cart that is fully mobile, led by co-facilitators, and goes out to meet the team members where they are in their work setting. The cart includes healthy snacks, meditation cards, resource materials internal to the health system, and worry stones, all presented with calming music in the background.*

*Team members were surveyed and 93% reported they agree or strongly agree that (i) increased knowledge would assist them in adult caregiving outside of work and (ii) increased knowledge about how to care for themselves was a result of their interaction with the AIR Cart and the Cart facilitator.*

***“The A.I.R cart is one way that hospital leadership shows they value me.”***

***“Thank you for demonstrating understanding and care for all who care for others at work and at home.”***

Constantly striving to increase the hack’s impact, the 2016 and 2017 Hacks also had a 2<sup>nd</sup> round, providing seed funding and Virginia-based pro-bono legal and business consulting to teams with the most promising tech tools. The seed funding was made possible in part through a Geriatric Training and Education grant secured by the Lindsay Institute team through a competitive grant process administered by the Virginia Center on Aging.

### **Recommendation 10**

The Governor’s office should provide recognition each year to the three winning teams of the Lindsay Institute for Innovations in Caregiving’s “Caring for the Caregiver” Hack to widely tout this one-of-a-kind, award-winning event in the Commonwealth, promote the technology innovations for caregivers created by the winning teams, and increase awareness of the family caregiving technology market for Virginia entrepreneurs and technology companies.

**GOAL IX: CAREGIVERS IN THE WORKPLACE** In order to successfully address the challenges of a surging population of older adults and others living with chronic conditions who have significant needs for long-term services and supports, the Commonwealth should explore methods to enable family caregivers to continue to work while at the same time supporting their care recipients at home and in the community, and avoiding unnecessary costs to the state’s health care system.

### **Background**

Increasingly, family caregivers maintain full or part-time employment while carrying out their caregiving responsibilities. Roughly 20% of Virginians and the American workforce as a whole serve as unpaid caregivers.<sup>15</sup> This number is expected to grow as individuals work longer and begin caring for spouses or other family members.

<sup>15</sup> <http://news.gallup.com/poll/148640/one-six-american-workers-act-caregivers.aspx>

## Recognize ♦ Support ♦ Transform

The federal Family Medical Leave Act (FMLA) allows workers to take 12 weeks of unpaid leave within a 12-month period and is available to individuals who work for a company that has 50 or more employees. A person considering FMLA must have been employed at the company for at least 12 months and worked at least 1250 hours in the period prior to FMLA leave. Today, only around 60% of the employees meet the FMLA criteria, but for many of those eligible workers FMLA isn't an option because it is unpaid and they can't afford to take it. Paid family leave laws have been enacted in five states: California, New York, New Jersey, Rhode Island, and Washington and in the District of Columbia. State laws differ in terms of the maximum amount of leave time allowed, eligibility requirements, extent of coverage, and method of how the insurance program is funded. According to *Supporting Caregivers in the Workplace: A Practical Guide for Employers*, "Employers that operate in multiple states with different paid family leave laws may face some administrative burdens in managing the varying eligibility and funding requirements of each state. All employers doing business in states that offer paid family leave will have to determine whether they will supplement an employee's income while he or she is on leave as the amount guaranteed to an employee only replaces a portion of his or her salary."<sup>16</sup> The 2018 Virginia General Assembly had three bills to enact paid family medical leave, and all of them failed. However, Senate Bill 790 (Senator Barbara Favola) requiring the Virginia Employment Commission to develop a plan for a paid family medical leave program was carried over in the Senate Finance Committee.

For working caregivers, achieving the balance between work and caregiving responsibilities can be difficult. In a national survey,<sup>17</sup> one in five retirees left the workforce earlier than planned because of having to care for an ill spouse or other family member. For those who remain in the workforce, nearly seven in 10 caregivers report making work accommodations because of caregiving.<sup>18</sup> These adjustments include arriving late or leaving early, taking time off, cutting back on work hours, changing jobs, or stopping work entirely.

---

<sup>16</sup> [https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving\\_Practical-Guide-FINAL.pdf](https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf)

<sup>17</sup> R. Hellman, C. Copeland, and J. Van Derhei, The 2012 Retirement Confidence Survey: Job Insecurity, Debt Weigh on Retirement Confidence, Savings. Issue Brief Number 369 (Washington, DC: Employee Benefit Research Institute, March 2012) - [https://www.ebri.org/pdf/briefspdf/EBRI\\_IB\\_03-2012\\_No369\\_RCS2.pdf](https://www.ebri.org/pdf/briefspdf/EBRI_IB_03-2012_No369_RCS2.pdf)

<sup>18</sup> National Alliance for Caregiving and AARP, Caregiving in the U.S. 2009 - [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf) --- Note, however, that a more recent version of the study puts the number at 61% making work accommodations - <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>

## Recognize ♦ Support ♦ Transform

Numerous studies have found that flexible workplace policies enhance employee productivity, lower absenteeism, reduce costs, and appear to positively affect profits.<sup>19</sup> They also aid recruitment and retention efforts, allowing employers to retain a talented and knowledgeable workforce and save the money and time that would otherwise have been spent recruiting, interviewing, selecting, and training new employees.

In addition to leave policies, there are other ways in which employers can support employee-caregivers in the workforce no matter an organization's size, industry or, resources. Of special concern are dual caregivers whose employment is as a caregiver and who are also caregivers at home. Flexible work policies for this group present special challenges, but they must be addressed to prevent risk to the caregiver and their care recipients at work and at home. The following checklist from *Supporting Caregivers in the Workplace: A Practical Guide for Employers* provides additional ideas for caregiving benefits and programs:

### Employer Caregiving Benefits and Programs Checklist

- Caregiver resource list**  
A list of public resources an employee caregiver can access, including financial planning and elder law assistance, directories of home care agencies, community-based services such as adult day care, and downloadable apps.
- Paid sick days that can also be used for employee or to care for a relative**
- Support groups for caregivers — led by experts or fellow caregivers**  
Employers can offer space and time for caregiving employees to meet, share resources and get support from one another. Some companies have such groups led by experts.
- In-house stress-reduction programs: Yoga, meditation, massage discounts**  
Yoga, meditation, massage and other types of stress reduction activities can help caregivers who are dealing with burnout or anxiety — and for employees in general. Some companies have the resources to provide such activities in house, while others can negotiate employee discounts.
- On-line or in-person coaching to assist in developing a care plan**  
Employees often need information and help specific to their caregiving situation as well as general assistance in navigating the world of caregiving.
- Employee Assistance Program (EAP) with caregiver resources**  
EAPs can offer caregiving-specific information, guidance and support to employees.
- FMLA (including help with filling out forms, etc.)**

---

<sup>19</sup> Council of Economic Advisors. Work-life balance and the economics of workplace flexibility. 2010. [December 10, 2015]. <https://www.whitehouse.gov/files/documents/100331-cea-economics-workplaceflexibility.pdf> AND AARP and ReACT. “Determining the Return on Investment: Supportive Policies for Employee Caregivers.” (2016) - <http://respectcaregivers.org/wp-content/uploads/2016/04/AARP-ROI-Report-FINAL-4.1.16.pdf>

## Recognize ♦ Support ♦ Transform

- Paid family leave**
- Digital tools to help employees manage caregiving**

There is a range of apps and other digital products employees can use to better manage caregiving responsibilities including digital tools to select and monitor paid caregivers, tap into social networks that can assist in caregiving tasks, and engage in passive monitoring of relatives at home.
- Subsidized back-up home care**

Some companies provide employees with subsidies that help cover the cost of home care services for a relative.
- Caregiving platform — one portal for all caregiver benefits and services from child care to care and assistance for parents, spouses and siblings**

Companies can provide one easy-to-access point of entry for information, resources and any benefits available to caregivers.
- Legal and financial counseling for employee and parents**

Companies with resources can offer one-on-one sessions with elder law and other attorneys and financial planners for themselves and family members.
- Health advocacy/navigator program for employees and their parents**

Companies can hire an outside vendor that assists with finding doctors, scheduling appointments, resolving benefits issues, getting second opinions, and explaining diagnoses.  
[https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving\\_Practical-Guide-FINAL.pdf](https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf), page 19.

### **Recommendation 11**

The Virginia Employment Commission should develop a plan for a program for private employers in the Commonwealth with 50 or more salaried employees to offer paid family-medical leave for their employees who are family caregivers.

### **Recommendation 12**

The Secretary of Commerce and the Secretary of Trade and Health and Human Resources should embark on a public awareness campaign to support the development and implementation of workplace policies, benefits, and programs to support family caregivers in the Commonwealth. In addition to family medical leave, this includes a caregiver resource list, support groups, in-house stress reduction programs, subsidized back-up home care, and legal and financial counseling for employees and parents.

### **Recommendation 13**

The Secretary of Administration should direct the Department of Human Resources Management to develop and implement policies and procedures to enable state employee family caregivers to be able to continue working while having sufficient time to care for aging or chronically ill family members.



## Recognize ♦ Support ♦ Transform

**GOAL X: DATA AND ADVOCACY** Establishing public policies to sustain and support family caregivers is an increasingly important public health issue requiring ongoing data collection and advocacy. Monitoring, tracking, and reporting on the experience of the Commonwealth’s family caregivers and advocating for their needs is a critical next step.

### Background

According to *From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Crisis* ([http://www.caregiving.org/wp-content/uploads/2018/01/From-Insight-to-Advocacy\\_2017\\_FINAL.pdf](http://www.caregiving.org/wp-content/uploads/2018/01/From-Insight-to-Advocacy_2017_FINAL.pdf)), “Surveillance data on public health topics is critical because it provides an evidence base upon which to make informed decisions about allocating resources, targeting programs, and developing policy.” The BRFSS is one of the primary sources of public health surveillance data in the United States. It is conducted annually to assess a variety of health-related topics including diet, physical activity, health care access, and health conditions. The Caregiver Module is optional and it screens all BRFSS respondents using the question, “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?” People who say “yes” are classified as caregivers and then report on the intensity and duration of their caregiving. During 2015, 24 states, including Virginia, included the Caregiver Module on their BRFSS. The Caregiver Module can raise awareness of the extent of caregiving and highlight current and future public health service needs for caregivers.

Virginia is very fortunate to have an established caregiver coalition with over 170 members. In addition to its successful grant-funded Lifespan Respite Voucher Program, the Virginia Caregiver Coalition (VCC) has undertaken efforts to help caregivers through information and referral services, educational outreach, and advocacy. The VCC brings together the personal experience and professional expertise that can meet the needs of family caregivers.

### **Recommendation 14**

The Secretary of Health and Human Resources should direct VDH to include the optional Caregiver Module questions in the BRFSS for 2019. This will cost \$27,000 (9 questions x \$3000 per question=\$27,000) and a similar amount every three years thereafter for the collection of the optional BRFSS Caregiver Module.

## Recognize ♦ Support ♦ Transform

### **Recommendation 15**

The Governor should introduce and General Assembly should enact a budget amendment in the amount of \$30,000 to provide DARS funding to allow the VCC to bring in speakers, do outreach, hold caregiver summits, and continue the development of the Virginia Family Caregiver Solution Center to house educational presentations.

## **CONCLUSION**

The Commonwealth can no longer relegate family caregivers to a personal or private role without providing more systematic approaches to their education and supports. It is time to recognize the prevalence of family caregiving, shine a spotlight on the demographic, societal, and technological trends that influence it, make it a public and societal concern, and demonstrate that our Commonwealth takes responsibility not only for its most vulnerable citizens but also for their family caregivers. The Family Caregiver Stakeholder Workgroup urges the Governor and General Assembly, state agencies, communities, health care and LTSS providers, employers and others to recognize and support family caregivers in order to improve and transform the Commonwealth's system of health care.

# Recognize ♦ Support ♦ Transform

## APPENDIX A

### Promising Practices for Including Family Caregiver Support in MLTSS

## *Promising Practices for Including Family Caregiver Support in MLTSS*

Entity	Contract Language	Assessment Tool	Family Caregiver Support
<p><b>TennCare CHOICES</b></p> <p><b>Links to additional information:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">TennCare CHOICES Website</a></li> <li>• <a href="#">Policy Manual</a></li> <li>• <a href="#">Assessment Manual</a></li> </ul>	<p>“At a minimum, for members in CHOICES Groups 2 and 3, the caregiver assessment shall include: (1) an overall assessment of the family member(s) and/or caregiver(s) providing services to the member to determine the willingness and ability of the family member(s) or caregiver(s) to contribute effectively to the needs of the member, including employment status and schedule, and other care-giving responsibilities; (2) an assessment of the caregiver’s own health and well-being, including medical, behavioral, or physical limitations as it relates to the caregiver’s ability to support the member; (3) an assessment of the caregiver’s level of stress related to care-giving responsibilities and any feelings of being overwhelmed; (4) identification of the caregiver’s needs for training in knowledge and skills in assisting the person needing care; and (5) identification of any service and support needs to be better prepared for their care-giving role.”</p>	<p>Assessment tools used by MCOs are proprietary – Patti Killingsworth (Assistant Commissioner and Chief of Long-Term Services and Supports, Division of TennCare, Long-Term Services and Supports) was unable to share.</p>	<ul style="list-style-type: none"> <li>• Assessment done at least annually.</li> <li>• If a significant change in circumstances occurs an assessment will be conducted. Also, the care coordinator can do an assessment whenever they deem necessary.</li> <li>• The assessment is used to develop a plan of care for the caregiver.</li> <li>• A family caregiver is defined as an individual who routinely provides unpaid care.</li> </ul>
<p><b>Healthy Connections Prime (South Carolina)</b></p> <p><b>Links to additional information:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Healthy Connections Prime Website</a></li> <li>• <a href="#">SC Healthy Connections Medicaid</a></li> </ul>	<p>Caregivers noted in multiple areas of the contract: see page 56 (2.5.7.2.4.), page 58 (2.6.3.3.1.), page 63 (2.6.6.7.5.3.), etc.</p> <p><a href="#">Full Version</a></p>	<p>Phoenix – automated case management system used by the state, includes a module on caregiver supports.</p> <p><a href="#">Additional information: see slides 16 – 56.</a></p>	<ul style="list-style-type: none"> <li>• Minimum of an annual assessment, done more frequently if the enrollee experiences a change in health status or triggering event (list in contract).</li> <li>• Care plan created, includes caregiver supports (example: 14 days of institutional respite care is available to the caregiver per year).</li> </ul>
<p><b>UnitedHealthcare</b></p>	<p><a href="#">Coverage Summary: Solutions for Caregivers</a></p>	<p>Information not found.</p>	<p>Medicare Advantage Plan members:</p> <ul style="list-style-type: none"> <li>• Geriatric experts and</li> </ul>

Source: [Family Caregivers and Managed Long-Term Services and Supports](#), November 2016

Additional Information: [Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers](#), November 2017

			<p>coaching available by phone (toll-free number).</p> <ul style="list-style-type: none"> <li>• Geriatric Care Managers provide one in-person assessment and up to six hours of phone consultation per year.</li> </ul> <p>Large Employers:</p> <ul style="list-style-type: none"> <li>• <a href="#">Solutions for Caregivers Portal</a> (includes resources and discounted products and services – case management offered by a team of clinicians can be added as an extra benefit).</li> </ul> <p>Medicaid Programs:</p> <ul style="list-style-type: none"> <li>• Caring for Caregivers Program (educational workshop series) and mindfulness training.</li> </ul>
<p><b>CalDuals Alzheimer’s (Cal MediConnect Dementia Project)</b></p>	<p><a href="#">Medi-Cal Managed Care Boilerplate Contracts</a></p>	<p><a href="#">Dementia Care Management Toolkit:</a></p> <ul style="list-style-type: none"> <li>• <a href="#">Tool for identifying family caregivers</a></li> <li>• <a href="#">Caregiver stress and strain instrument</a></li> <li>• <a href="#">Caregiver needs assessment</a></li> </ul>	<ul style="list-style-type: none"> <li>• Caregivers are identified and assessed in order to develop a plan of care.</li> <li>• <a href="#">Plain language fact sheets</a> on home safety, anger/frustration/fighting, getting lost, bathing, medications, and hallucinations are available as a resource for caregivers.</li> <li>• Training on dementia available for care managers.</li> </ul>

# Recognize ♦ Support ♦ Transform

## APPENDIX B Caregiver Resources

Eldercare Locator: <a href="http://www.eldercare.gov">www.eldercare.gov</a> or <a href="tel:800-677-1116">800-677-1116</a>	A public service of the U.S. Administration on Aging that connects caregivers to local services and resources for older adults.
Administration on Community Living (ACL): <a href="http://www.acl.gov">www.acl.gov</a>	The federal agency responsible for advancing the concerns and interests of older people. The website has a variety of tools and information for older adults and family caregivers.
NIH Senior Health: <a href="http://www.nihseniorhealth.gov">www.nihseniorhealth.gov</a> or <a href="tel:800-222-2225">800-222-2225</a>	Fact sheets from the U.S. National Institutes of Health can be viewed online or ordered for free.
AARP Caregiving Resource Center: <a href="http://www.aarp.org/caregiving">www.aarp.org/caregiving</a>	Your one-stop shop for tips, tools and resources while caring for a loved one.
Family Caregiver Alliance: <a href="http://www.caregiver.org">www.caregiver.org</a> or <a href="tel:800-445-8106">800-445-8106</a>	Tools and resources for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.
National Alliance for Caregiving: <a href="http://www.caregiving.org">www.caregiving.org</a>	This organization is dedicated to improving the quality of life for caregivers and those they care for through research, innovation and advocacy.
Rosalynn Carter Institute for Caregiving: <a href="http://www.rosalynncarter.org">www.rosalynncarter.org</a>	Created to support caregivers, both family and professional, through efforts of advocacy, education, research and service.

# Recognize ♦ Support ♦ Transform

## APPENDIX C

### Virginia Family Caregiver Stakeholder Workgroup

Alzheimer’s Disease and Related Disorders Commission	Lory Phillippo, MPH, OTR/L, Chair Laura Bowser, Vice Chair
AARP	David DeBiasi, RN, Associate State Director-Advocacy
Virginia Caregiver Coalition	Ashley Chapman Kenneth, Chair, Director of Policy and Advocacy for the National MS Society Mauretta Copeland Kathy Dial Christine Jensen, Ph.D. Director, Health Services Research, Riverside Center for Excellence in Aging and Lifelong Health Monica Uhl, M.A., Consultant Jane Ward Solomon
Commonwealth Council on Aging	Richard Lindsay, M.D., Lindsay Institute for Innovations in Caregiving
Northern Virginia Aging Network (NVAN)	Jane King
VirginiaNavigator	Adrienne Johnson, Executive Director Katie Benghauser, MS, Director of Operations
Virginia Department for Aging and Rehabilitative Services, Division for Community Living	Marcia DuBois, Deputy Commissioner Amy Marschean, J.D., Senior Policy Analyst Liz Havenner, MSW, LSW, Human Services Program Coordinator Kathy Miller, MS, RN, MSHA, Director of Programs Devin Bowers, MPH, Dementia Services Coordinator

# Recognize ♦ Support ♦ Transform

## APPENDIX D Letters of Support





COMMONWEALTH OF VIRGINIA  
*Alzheimer's Disease and Related Disorders Commission*  
August 22, 2017

Lory Phillippo, MPH, OTR/L, Chair  
Laura Bowser, Vice Chair  
Rona Altschuler  
Vivian Bagby, RN, MS  
Sharon E. Davis  
Chris Desimone, Esq.  
Julia T. Dillon  
Karen Garner  
Janet L. Honeycutt  
Valerie Hopson-Bell  
G. Richard Jackson, MPA, CSA  
Katherine A. Kennedy  
Carol Manning, Ph.D, ABPP-CN  
Charles Martino, CSA, AIA  
Courtney Tierney, MSW

Liz Havenner  
Human Services Program Coordinator  
Department for Aging and Rehabilitative Services  
1610 Forest Avenue, Suite 100  
Henrico, VA 23229

**RE: Recommendations for Improving Family Caregiver Support  
in Virginia 2018**

Dear Ms. Havenner:

We are writing in support of the Virginia Family Caregiver Stakeholder Workgroup's goals and recommendations in the report referenced above. Alzheimer's disease and related disorders (ADRD) are progressive, neurodegenerative conditions that result in cognitive, social, and physical functional decline, as well as behavioral and psychological symptoms. Most persons with ADRD live at home and are cared for by family members. As symptoms worsen with the progression of a relative's ADRD, the care required of family members can result in increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment and depleted income and finances. Alzheimer's Association. 2014. *2014 Alzheimer's disease fact and figures*.  
[https://www.alz.org/downloads/facts\\_figures\\_2014.pdf](https://www.alz.org/downloads/facts_figures_2014.pdf)

Specifically, we support the recommendations that provide increased awareness of family caregivers so that they are routinely identified and have their needs assessed. We further support family centered care coordination, respite services, data collection, and training of health care providers to recognize and engage family caregivers and to provide supports and referrals to them. We stand ready to support the Commonwealth to improve family caregiver support in Virginia and the additional resources that will be required to do so.

Thank you for this opportunity to comment.

Sincerely,

Lory L. Phillippo, MPH, OTR/L, Chair  
Alzheimer's Disease and Related Disorders Commission

cc: Marcia DuBois, Deputy Commissioner, Division for Community Living, DARS

[www.alzpossible.org](http://www.alzpossible.org)  
[vda.virginia.gov/alzcommission.asp](http://vda.virginia.gov/alzcommission.asp)

Department for Aging and  
Rehabilitative Services (DARS)  
Virginia Division for the Aging  
1610 Forest Avenue, Suite 100  
Richmond, Virginia 23229

[aging@dars.virginia.gov](mailto:aging@dars.virginia.gov)  
(804) 662-9333  
Fax (804) 662-7035



April 30, 2018

Liz Havenner  
Human Services Program Coordinator  
Dept for Aging and Rehabilitative Services  
1610 Forest Avenue, Suite 100  
Henrico, VA 23229

Dear Ms. Havenner,

I am writing on behalf of the National Multiple Sclerosis Society (the Society) in support of the findings and recommendations presented by the Virginia Family Caregiver Stakeholder Workgroup. I am the chair of the Government Relations Advisory Committee (GRAC) for the Society in Virginia, and I am also a Nurse Practitioner and Co-Director of a Multiple Sclerosis Comprehensive Care Center in Fredericksburg, VA.

As a Nurse Practitioner, I directly care for approximately 1,100 Virginians with chronic health conditions annually. I interact with family caregivers every day and see that we are not providing them with the resources they need to deliver care to their loved ones. Family caregivers are critical to the health and wellbeing of my patients, but due to the lack of resources they often struggle financially, emotionally, and physically. Most of the caregivers I interact with have had to reduce their work hours or leave their jobs altogether, placing additional financial stress on the family. Often, they have no access to respite care, and as a result they do not get any break from their caregiving duties during the week. This increases caregiver stress, placing an unnecessary and preventable emotional burden on the patient and family. Lack of respite care also prevents caregivers from attending to their own medical needs, which increases their risk of also becoming disabled and prevents them from effectively delivering care. As a healthcare provider I often feel unprepared to address many of these challenges, as there simply are not many resources for me to utilize.

**JOIN THE MOVEMENT**



The GRAC, the Society, and I strongly support the recommendations of the Virginia Family Caregiver Stakeholder Workgroup, which would provide additional resources and education, increase awareness, and lessen the burden of family caregivers throughout the state of Virginia. If we can be of any support to the Department of Aging and Rehabilitative Services to accomplish the goals and recommendations outlined in the report, please let me know.

Sincerely,

A handwritten signature in black ink that reads "Stephanie Buxhoeveden". The signature is written in a cursive, flowing style.

Stephanie Buxhoeveden, MSN, MSN, FNP-BC

Nurse Practitioner, Co-Director of the MS Center at Neurology Associates of Fredericksburg  
Chair, Virginia Government Relations Advisory Committee  
National Multiple Sclerosis Society

JOIN THE MOVEMENT

# **Response of the Northern Virginia Aging Network (NVAN) to the Virginia Family Caregiver Stakeholder Workgroup Findings and Recommendations**

**May 1, 2018**

The reviewers for NVAN agreed that the Findings and Recommendations of the Virginia Family Caregiver Stakeholder Workgroup provide an excellent summary of the caregiver data that was reviewed. The background that describes the Commonwealth's deficiencies in support for caregivers makes a powerful case for taking significant action to improve the environment in which family caregivers must function in the Commonwealth.

The Findings and Recommendations are both informative and persuasive regarding the urgent need for increasing support for caregivers and are comprehensive, covering the range of caregiver needs. The emphasis on the need for cultural competence for medical and health care providers is important, to address the growing diversity of Virginia's population.

The proposals for legislative, regulatory and private actions offer solutions that can diminish the often devastating consequences of long-term caregiving by family caregivers. The recommendations also take into account the prospective role of the private sector. Employers, for example, can have a profoundly beneficial effect on caregivers if they take the steps to reduce their stress and enable them to work while providing care to a loved one.

The recommendations in the report are preceded by a paragraph that states the case succinctly:

"The Commonwealth can no longer relegate family caregiving to a personal or private role without providing more systematic approaches to their education and supports. It is time to recognize the prevalence of family caregiving, shine a spotlight on the demographic, societal, and technological trends that influence it, make it a public and societal concern, and demonstrate that our Commonwealth takes collective responsibility for its most vulnerable citizens and their family caregivers."

**The Role of NVAN:** NVAN develops a platform prior to each General Assembly Session, usually comprised of three legislative and three budget proposals. For the 2018 Session, NVAN supported the DARS study, which has resulted in the Findings and Recommendations currently under consideration.

Participants in NVAN are considering the Workgroup recommendations that require legislative action as it selects its priorities for 2019. It is possible that NVAN will choose one of the recommendations as a legislative or budget proposal. (The selection will occur on May 15.) The recommendations requiring legislative action are the following, as specified in the Findings and Recommendations of the Workgroup:

- A budget amendment to DARS for approximately \$3 million in funding to restore funding for home-based care to SFY 2009 levels,
- A tax credit for working caregivers that could be based on income eligibility, maximum credit amount, qualified expenses, refundable designation, etc. This financial assistance enables caregivers to continue their caregiving roles.
- Medicaid coverage of telehealth services.
- A budget amendment for \$100,000 annually for the DARS Lifespan Respite Voucher Program.
- Paid family leave provided by employers of 50 or more employees in the Commonwealth. This recommendation of the Workgroup would require the Virginia Employment Commission to develop a plan, which ultimately would require legislative action.

The recommendations that do not require legislative action could have very beneficial consequences for caregivers. Participants in NVAN are able to be supportive of them in their roles as advocates in their communities and in their work with residents, providers, local and state government, the faith-based community and others.



COMMONWEALTH OF VIRGINIA  
*Commonwealth Council on Aging*

July 11, 2018

*Veronica Williams, Esq., Chair*

*Beverly Soble, Vice Chair*

*Davis Creef*

*Deborah Davidson, RN*

*Jennifer L. Disano*

*David M. Farnum, Secretary*

*Joni C. Goldwasser, DNP, NP*

*Andrew B. Hamilton*

*Carter R. Harrison*

*Tresserlyn L. Jones*

*Richard W. Lindsay, MD*

*Shewling Moy*

*Diana M. Paguaga*

*Kathryn B. Reid, PhD, RN*

*Vernon Wildy*

*Erica Wood, Esq.*

*Ex-Officio Members*

*Hon. Daniel Carey, MD*

*Kathryn Hayfield*

*Tara Ragland*

*Terry A. Smith*

*Leigh Wade*

[www.vdu.virginia.gov/boardsandcouncils.htm](http://www.vdu.virginia.gov/boardsandcouncils.htm)

*Virginia Department for Aging and  
Rehabilitative Services  
1610 Forest Avenue, Suite 100  
Henrico, Virginia 23229*

[aging@dars.virginia.gov](mailto:aging@dars.virginia.gov)

(804) 662-9333

Fax (804) 662-7035

Liz Havenner  
Human Services Program Coordinator  
Department for Aging and Rehabilitative Services  
1610 Forest Avenue, Suite 100  
Henrico, VA 23229

**RE: Recommendations for Improving Family Caregiver Support  
in Virginia 2018**

Dear Ms. Havenner:

We are writing in support of the Virginia Family Caregiver Stakeholder Workgroup's goals and recommendations in the report referenced above. The purpose of the Council pursuant to Virginia Code § 51.5-127 is to promote an efficient, coordinated approach by state government to meeting the needs of older Virginians.

By 2026, the leading edge of the baby boomers will enter their 80s, placing new demands on both the health care and long term services and supports systems. Between ages 85 and 89 years, more than half of older adults (58.5%) require a caregiver's help because of health problems and from age 90 years and onward, only a minority of individuals (24%) do not need some assistance from a caregiver.

<https://www.nap.edu/read/23606/chapter/1>

We wholeheartedly agree with the report's conclusion that the Commonwealth must take collective responsibility for its most vulnerable residents and their family caregivers. The Council promotes family-centered care and urges long overdue recognition for family caregivers and funding for and endorsement of the supports outlined in the report recommendations.

Sincerely,

Veronica Williams, Esq.  
Chair