

Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Virginia Department for Aging and Rehabilitative Services (DARS)**

Funding Period: **2014-2017**

Primary Goal: **Expand and embed a sustainable, coordinated system of affordable and accessible, person/family-centered, quality lifespan respite support throughout Virginia, for families who provide unpaid care to individuals of any age with any disability, chronic disease, and/or special need.**

Key Performance Measures	Notable Achievements
<p>Outcomes measures included: the extent to which volunteers and workers felt prepared to provide respite support to families; the extent to which volunteers, workers and caregivers felt that training was flexible, convenient, and easy to use; whether caregivers felt more confident and better prepared to utilize respite supports; the extent to which families receiving voucher support felt less overwhelmed, experienced financial relief, enhanced relationships, and/or reduced anxiety; increases in outreach by lifespan respite programs to rural regions and to limited English-speaking populations; demographic data; cost per respite unit data; improved understanding among employers about the impact that caregiving has on the caregiver and company; and improved understanding among legislators about the fiscal impact of caregiving.</p>	<p>Virginia Lifespan Respite Voucher Program (VLRVP), a statewide program, covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, DARS provided 711 families, on average, 41 hours of respite care and reached caregivers in urban as well as isolated underserved areas, and in diverse cultural communities.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1: Expand/enhance respite services through an online training program.</p> <ul style="list-style-type: none"> • DARS reported great success providing caregivers with information, education and resources through Virginia Caregiver Coalition (VCC) educational videoconferences; VCC provided 18 educational videoconferences, with 23 participants on average in attendance for each event during the funding period. Participants from across the Commonwealth are able to call in on their own or attend at one of their local VCC sites. • Overwhelmingly, participants “Agreed” when asked if “the information presented will be useful to [them]” for all educational presentations. Examples of program evaluation feedback include: <ul style="list-style-type: none"> ▪ “Personally strengthened me with personal experiences.” ▪ “Insightful thoughts and ideas that can be incorporated with personal life.” ▪ “Learned about services in the community...” ▪ “This is a resource I will provide my community organization.” ▪ “Community information and programs were most valuable.” 	<p>State Respite Coalition/Organization Role</p> <ul style="list-style-type: none"> • The Virginia Caregiver Coalition (VCC) and its network of local VCC sites are key partners and provide the infrastructure to reach Virginia caregivers across the state, across geographic areas and cultural communities. <p>Aging and Disability Resource Center (ADRC) Role</p> <ul style="list-style-type: none"> • At the outset of project funding, 4,564 caregivers had received information and education related to respite and referrals to respite support (a 30% increase over the previous year) through Virginia’s ADRC

Objective 2: Improve statewide dissemination/coordination of respite care through ADRC and VCC networks.

- Respite supports are listed on the ADRC service provider database, and Virginia's online caregiver solution center.
- Members of the VCC and other caregivers serve on Advisory Councils for Aging and Disability Resource Centers (ADRC) and advocate for issues related to lifespan respite. The ADRC has become a valuable resource for information on respite throughout the Commonwealth.

Objective 3: Increase access through a Lifespan Respite Voucher Program.

- Virginia Lifespan Respite Voucher Program (VLRVP), a statewide program, covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, DARS provided 711 respite vouchers that reached caregivers in isolated underserved areas and cultural communities. Twelve percent of those benefiting from the voucher program resided in rural areas. Additionally, the VLRVP reached limited English-speaking populations with 13.2% of vouchers benefiting Asian populations, 5.3% benefiting Hispanic/Latino populations, 3.9% benefiting Multi-racial populations, and .3% benefiting Native American populations.
- Families receiving a respite voucher generally reported an improvement in their overall well-being and happiness. A few examples from client satisfaction surveys include:
 - The program "gave me peace of mind while I was away."
 - "Respite services are very expensive, so we rarely use them. This allowed us to do something special with our other two children."
 - "Thank you so much. I feel like I have been renewed."
 - "Thank you for the respite program! It helped me get a much-needed break from the stress of managing two kids with special needs."

Objective 4: Develop/implement strategies for working with the private-sector business community.

- The VCC Advocacy Committee worked to raise awareness through their various networks, providing education and research, but with minimal impact. This remains a priority to the VCC as they endeavor to educate employers on the impact of caregiving on both their employees and their businesses.

Objective 5: Identify, cultivate, and secure new and sustainable sources of funding.

- DARS and the VCC Advocacy Committee worked with legislators to increase their understanding of the fiscal impact of caregiving on Virginia's caregivers and have requested funding for caregiver support. As a result, two legislators sponsored budget amendments. Additional funding has not been awarded at this time, but the Committee's efforts will continue with the upcoming General Assembly session in January 2018. Also, DARS is spearheading a Caregiver Taskforce composed of stakeholders, including the VCC and AARP, that are identifying resources and challenges for family caregivers and will be making recommendations in a report to the General Assembly.

network as a result of a strong VCC, DARS and ADRC partnership.

State and Community Partners

- Virginia Caregiver Coalition (VCC), with more than 185 members across the state (an increase of 45 members during the funding period)
- ADRCs
- Area Agencies on Aging (AAAs)
- Partnership for People with Disabilities, Virginia's University Center for Excellence in Developmental Disabilities (UCEDD), affiliated with Virginia Commonwealth University (VCU)
- VirginiaNavigator, host and administrator of the Family Caregiver Solution Center, the umbrella for SeniorNavigator and disAbilityNavigator, managed through one 501(c)3 non-profit organization, and focused on supporting individuals in maintaining quality of life within their environment of choice. VirginiaNavigator provides comprehensive information on issues such as health, financial concerns, legal questions, health facilities, housing options, transportation, exercise programs, advocacy, and more.



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Lifespan Respite Care Program



Lifespan Respite Grantee Lead Agency: **Virginia Department for Aging and Rehabilitative Services (DARS)**

Funding Period: **2018-2021**

Primary Goal: **Expand and enhance Virginia’s coordinated system of affordable and accessible, person/family-centered, quality lifespan respite support throughout the Commonwealth, for: families who provide unpaid care to individuals, of any age, with a diagnosis of dementia; for grandparents or relative caregivers providing care to a child not more than 18 years of age or an individual 19 to 59 years of age who has a severe disability; or a relative of a child by blood, marriage, or adoption.**

Key Performance Measures	Notable Achievements
<p>Data are collected to document the following identified outcomes: the number of new partnerships that provide program referrals; identification of possible alternative funding and community resources; benefits of respite as reported by caregivers; and the development of an educational series for target populations. Additionally, the Virginia Caregiver Coalition (VCC) documents activities that encourage additional membership; evidence of the State’s understanding of gaps in services and resources available to caregivers; and the accuracy of data entry in the State Lifespan Voucher Assistant. The grantee generates quarterly and yearly data based reports indicating areas for program improvement. Products include: Survey of Grandparents and Relative Caregivers community resources; Pre/Post Caregiver Burden Inventory survey; a Service Gap Report; and Lessons Learned.</p>	<p>The Virginia Caregiver Coalition (VCC) began 15 years ago with 22 founding members and now numbers more than 200. VCC works to improve care recipients’ and their families’ experience of caregiving through education, advocacy and access to resources. The VCC highlights specific challenges inherent to targeted populations by dedicating at least one educational series to each respective population. The VCC also seeks out and encourages membership within targeted populations. Educational topics shared through regular VCC meetings have included: Unique Approaches to Double Duty Caregivers, Supporting Dementia Care Partners, Advance Directives, Managing Other Peoples’ Money, Age Friendly Communities and Medicaid Expansion.</p>

Key Objectives, Activities and Outcomes	Coalition, ADRC and Community Partners
<p>Objective 1: Increase outreach to target caregivers of individuals with dementia and grandparents or relative caregivers providing care to a child or an older individual with a severe disability.</p> <ul style="list-style-type: none"> • Virginia is enhancing their statewide lifespan respite care system by forging new partnerships with memory clinics, outpatient specialty clinics, local Alzheimer’s chapters, the Healthy Grandparents Program and other kinship groups in each major geographical region of the Commonwealth as a source for referrals to better penetrate proposed target populations. <p>Objective 2: Increase caregiver coalition capacity within target populations.</p> <ul style="list-style-type: none"> • Using the network of family caregivers, care recipients and public/private agencies within the Virginia Caregiver Coalition (VCC) in the planning and implementation of proposed 	<p>State Respite Coalition/Organization Role</p> <ul style="list-style-type: none"> • Established in 2004, the Virginia Caregiver Coalition (VCC) continues to be a strong ally for Virginia’s caregivers and has boosted membership to nearly 200 agencies and family members across the lifespan, supporting individuals of all ages and disabilities. In addition, members of the VCC and other caregivers now serve on Advisory Councils for Aging and Disability Resource Connections (ADRC), advocating for issues related to lifespan respite. DARS

respite care activities, a current MOU between the VCC and DARS continues a partnership of education and outreach to Virginia's caregiving community.

Objective 3: Expand the Virginia Family Caregiver (VFC) Solution Center to include resources that assist grandparents and relative caregivers.

- Virginia has a network of 343 strategically located VirginiaNavigator Centers that provide assistance to older adults, individuals with disabilities, and family caregivers, including Virginians who don't have a computer or internet access. These Centers are partnerships between VirginiaNavigator and community-based supports such as libraries, faith-based communities, hospitals, community centers, transportation providers and other community-based organizations, whose staff is trained to use VirginiaNavigator and its family of websites, SeniorNavigator and disAbilityNavigator. Because the Virginia Family Caregiver (VFC) Solution Center is hosted by VirginiaNavigator, the Centers' staff were trained also on the Solution Center. During 2017, the VFC Solution Center reported 588 site visits.

Objective 4: Convene a stakeholder group to conduct a year-long gap assessment of Virginia's family caregiving issues and long-term services and supports to expand the No Wrong Door (NWD) Resource Database.

- The grantee is convening a stakeholder group with representatives from the VCC, AARP, Commonwealth Council on Aging, Partnership for People with Disabilities, Virginia Alzheimer's Commission, and VirginiaNavigator, (in consultation with Virginia's NWD Director) to conduct a year-long assessment of the NWD Resource Database and identify caregiver resources and service gaps.

Objective 5: Increase knowledge and use of respite among family caregivers of individuals with dementia and grandparents or relative caregivers.

- Grant funds support expanding the VFC Solution Center to include resources for grandparents and relative caregivers. Further, this funding opportunity allows the VCC to grow as it focuses on another caregiver target and network system, strengthen their network of partners such as memory centers and kinship groups, and allow DARS to identify unmet respite needs of caregivers of individuals with dementia and grandparents and relative caregivers.

Objective 6: Utilize the NWD System to make automated referrals, securely share individual-level data and track individual progress.

- Applicants using VirginiaNavigator are provided information and referrals for programs and other resources, identified through person-centered practices, as a good match for their individual needs, using the NWD System.

Objective 7: Combine gap-assessment data with NWD System data to better understand and address needs across the state.

- This grant helps NWD incorporate referrals for respite vouchers, which allows automated referrals, secure exchange of individual-level data, and a comprehensive tracking tool and robust reporting to ensure streamlined access to the voucher program, provide ongoing support to caregivers and capture valuable data for outcome measures.

Objective 8: Show a measurable increase in the number of families experiencing temporary relief of caregiving burden.

- The State collects data on the benefits of respite as reported by caregivers, including the extent to which caregivers who receive voucher support feel financial relief, reduced stress

and the VCC have worked as partners for eight years to establish an integrated lifespan respite infrastructure in the Commonwealth of Virginia.

Aging and Disability Resource Center (ADRC) Role

- DARS Division for the Aging oversees 25 Area Agencies on Aging (AAAs).
- Members of the VCC and other caregivers across Virginia serve on Aging and Disability Resource Connections (ADRC) state and local advisory committees, advocating for issues related to lifespan respite.

State and Community Partners

- Virginia Caregiver Coalition (VCC)
- AARP
- Commonwealth Council on Aging
- Partnership for People with Disabilities
- Virginia Alzheimer's Commission
- VirginiaNavigator
- UVA Memory Clinic
- Riverside Center for Excellence in Aging and Lifelong Health
- Carilion Clinic for Healthy Aging
- REACH
- Healthy Grandfamilies

and/or anxiety, enhanced relationships with family members, and improved quality of life as a result of respite care.

Objective 9: Reduce stress of caregivers of individuals with dementia and grandparents or relative caregivers.

- Grant funds provide 450 families with vouchers worth up to \$400 to include resources for grandparents and relative caregivers.



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