CHCS Center for Health Care Strategies, Inc.



Strengthening Family Caregiving Programs and Policies through Collaboration: Lessons from Six States

September 2020

By Courtney Roman, Michelle Herman Soper, Matthew Ralls, and Giselle Torralba, Center for Health Care Strategies











IN BRIEF

Over the last five years, the number of adults in the United States caring for a family member or friend age 50 or older has increased to more than 40 million individuals. Ensuring that family caregivers have what they need to support their loved ones with complex needs, maintain their own well-being, and improve the health outcomes of older adults is critical especially during the COVID-19 pandemic. With support from The John A. Hartford Foundation, the Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation, this brief highlights the innovative cross-sector work of six states that participated in a Center for Health Care Strategies (CHCS)-led learning collaborative. It describes the key elements needed for foundational state program changes to support family caregivers more effectively. In fall 2020, a new set of states will have the opportunity to join the next phase of this project.

he number of adults in the United States caring for a family member or friend age 50 or older has increased by more than eight million in the last five years to roughly 41.8 million caregivers.¹ Family caregiving is an activity that spans generations in all regions of the country — across all racial, ethnic, and cultural identities as well as income and education levels.² Because individuals are living longer and are seeking to stay in their homes and communities as opposed to nursing facilities, the need for family caregivers will continue to grow.

The work that family caregivers perform is vital to individuals who want to remain at home and is valuable to the health care system overall. By helping older adults live at home longer, family caregivers may delay the need for costly home health services or long-term care facility stays.³ Estimates suggest family caregiving is worth \$470 billion annually, providing significant savings to the health care system.⁴ Furthermore, family caregivers can potentially improve the quality of health care and outcomes by reinforcing provider care instructions at home, administering medications, and providing emotional support. In a recent AARP study, 88 percent of primary care physicians reported that they believed family caregivers improved patient health outcomes.⁵

This role, however, does not come without challenges or strain.⁶ Family caregivers frequently take on tasks that professional health care providers or direct care workers would otherwise perform, on top of managing household chores, navigating health care benefits for their loved ones, and coordinating care needs that are complex. The combination of these responsibilities often negatively impacts family caregivers' physical and emotional health and well-being.⁷ In a report from the National Alliance for Caregiving and AARP, 23 percent of family caregivers said that the work has made their health worse and a similar percentage claimed it is difficult to manage their own health.⁸ Nearly two thirds of family caregivers are working outside the home in addition to their caregiving responsibilities, and around half report going into work late, leaving early, or taking time off to accommodate care.⁹ One in 10 respondents report retiring early or leaving the workforce entirely, leading to a significant loss in wages and retirement savings.¹⁰ Furthermore, the COVID-19 pandemic has put even more stress on family caregivers. Many families sheltering in place with older adults are serving as full-time caregivers for the first time, without supports and training.

In 2017, the National Academies of Sciences, Engineering, and Medicine report, Families Caring for an Aging America, ¹¹ made several recommendations for effectively engaging and supporting the nation's family caregiver workforce. Specifically, the report urged the federal government to accelerate the pace of change in addressing the needs of family caregivers, which resulted in the January 2018 passage of the RAISE Family Caregivers Act. The report also recommended that state governments should learn from each other to more effectively address the health. economic. and social challenges of family caregivers of older adults. Toward this goal, with support from The John A. Hartford Foundation, the Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation, the Center for Health Care Strategies (CHCS) launched the Helping States Support Families Caring for an Aging America initiative. In its first phase, the initiative supported six states - Alabama, Idaho, Iowa, New Hampshire, South **Carolina**, and **Virginia** — in advancing policy and program changes to support family caregivers and learning from each other during the process. Over 24 months, participating states focused on strengthening strategies to identify family caregivers, collecting data through new statewide family caregiver assessments, determining how to assess and streamline existing programs and supports, and improving access to respite care.

HELPING STATES SUPPORT FAMILIES CARING FOR AN AGING AMERICA INITIATIVE

Through the *Helping States Support Families Caring for an Aging America* initiative, the Center for Health Care Strategies (CHCS) is working with states committed to developing policies or programs to support family caregivers and address the challenges of an aging population. With support from The John A. Hartford Foundation, the Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, and the Gordon and Betty Moore Foundation, the initiative is helping states develop strategies to assist family caregivers. From



May 2018 through September 2020, CHCS provided technical assistance to six states that participated in the learning collaborative, including strategic guidance, action planning, coaching conference calls, webinars, and one in-person meeting. States received tailored support from CHCS while also benefitting from peer-sharing with fellow participating states. Phase II of this project, made possible by The John A. Hartford Foundation, will launch in October 2020, with a new cohort of states that are interested in improving family caregiving policies and programs.

Drawing from these states' experiences in implementing new activities to support family caregivers, this brief outlines the key foundational elements across state efforts and explores what is needed at the state and national levels to advance innovations for family caregivers. See Exhibit 1 for participating states' focus areas and summary of outcomes to date.

STATE	PROJECT FOCUS AREA	HIGHLIGHTS
Alabama	Increase respite care access by establishing statewide worker standards and strengthening workforce capacity.	Developed a funding plan for an academic pilot program for respite care training at Alabama community colleges.
Idaho	Strengthen partnership with Idaho Medicaid to identify ways to bolster family caregiver services and supports.	Implementing a two-year pilot supported by Idaho Medicaid to improve coordination for family caregivers through use of a family caregiver assessment and resource database.
lowa	Streamline service delivery processes and collect more consistent data to report National Family Caregiver Support Program activities.	Developed a uniform family caregiver assessment tool that is now used in the state's six Area Agencies on Aging.
New Hampshire	Develop a formal approach at the state leadership level to prioritize family caregiver support across various agencies.	Established the Department of Health and Human Services' Family Caregiver Integration Team, a first of its kind at the agency.
South Carolina	Assess statewide family caregiver policies and programs and develop recommendations for how to increase family caregiver capacity.	Conducted a statewide environmental scan of family caregiving policies and programs to identify system strengths and gaps.
Virginia	Increase family caregiver supports available to Medicaid beneficiaries enrolled in the state's managed long-term services and supports program.	Established a cross-sector work group (including community groups and Medicaid health plans) tasked with identifying new ways to better support family caregivers.

Key Elements Needed for Foundational Program Changes to Support Family Caregivers

ELEMENT 1: Prioritize Cross-Sector Engagement

State agencies and the family caregiving programs they house often exist in silos, which can duplicate work and create missed opportunities for improving or expanding family caregiving supports. A cross-sector approach to improvement that includes various state agencies and divisions, private sector programs, and community groups can expand the number of family caregivers supported, avoid duplication, and use resources more effectively. Additionally, state agencies often operate with limited resources, staff capacity, and time. Collaboration across state agencies and private sector programs can better target resources dedicated to family caregiving supports and accelerate progress in meaningfully supporting family caregivers. As one South Carolina team member noted, "when you are working with family caregivers, you soon realize how

many state agencies they have to touch [to get help]. That's when you recognize that [working in] silos will not work...we end up missing the 360 degree needs of family caregivers."

Through this initiative, opportunities to test cross-sector partnerships helped states to think critically about which agencies, departments, and community organizations should be at the table to create meaningful change. In several cases, this meant working with external organizations, such as Area Agencies on Aging (AAAs), Alzheimer's Association chapters, and AARP state offices.

A few of the participating states focused on strengthening relationships and collaboration across state agencies on aging and Medicaid. The population of older adults who are eligible for Medicaid is projected to grow over the next several years, and state agencies on aging often serve older adults who have lower incomes but who are not yet eligible for Medicaid. In response, Alabama, Idaho, and Virginia, brought Medicaid and aging agencies together to develop initiatives that incorporated family caregiving supports as an integral "When you are working with family caregivers, you soon realize how many state agencies they have to touch [to get help.] That's when you recognize that [working in] silos will not work...we end up missing the 360 degree needs of family caregivers."

- South Carolina Family Caregiving Team Member

component across home- and community-based services as opposed to a separate program. Exhibit 2 shows the diverse organizations within the cross-sector partnerships that participating states established to improve family caregiver supports.

These cross-agency efforts created opportunities for state partners to uncover and build on work already in progress. For example, Virginia's Department of Medical Assistance Services (DMAS) was seeking to better support family caregivers through Medicaid services. By partnering with the Department for Aging and Rehabilitative Services (DARS), DMAS was able to access data obtained by DARS regarding service utilization for Medicaid enrollees and those who may become Medicaid eligible. The DMAS and DARS partnership allowed the two agencies to access shared resources and build on prior respective program work, preventing duplication of efforts.

Exhibit 2: State Cross-Sector Family Caregiving Teams

STATE	CROSS-SECTOR TEAMS	
Alabama	Department of Human Resources; Department of Senior Services; Alabama House of Representatives; and Alabama Medicaid Agency	
Idaho	Idaho Commission on Aging; Idaho Caregiver Alliance; Area V Agency on Aging; and Department of Health and Welfare (Medicaid)	
lowa	Department on Aging; Aging Resources of Central Iowa; Elderbridge AAA; Northeast Iowa Area Agency on Aging; Heritage AAA; Milestones AAA; and Connections AAA	
New Hampshire	Department of Health and Human Services divisions, including: Children, Youth, and Families; Long- Term Services and Supports; and Behavioral Health	
South Carolina	Department of Health and Human Services; Department on Aging; Alzheimer's Association; AARP South Carolina; and South Carolina Institute of Medicine and Public Health	
Virginia	Department for Aging and Rehabilitative Services and Department of Medical Assistance Services	

While the benefits of establishing a cross-sector team are numerous, there are some challenges. First, finding mutually available time to come together for project meetings can be difficult. Staff often work in different areas of the state and have busy schedules, making it difficult to identify availability to meet in-person or even virtually. One strategy used by states to help offset these challenges was to designate a point person for their team to coordinate meeting dates, schedules, and other communications. Second, bringing various work approaches and cultures together can take time to adjust to as a team. States shared that being flexible and collaborative was key.

STATE EXAMPLES: PRIORITIZE CROSS-SECTOR ENGAGEMENT

New Hampshire's team sought to develop a formal approach at the state leadership level to prioritize family caregiving across various agencies, especially those within the Department of Health and Human Services (DHHS). The resulting family caregiving workgroup included DHHS divisions that all have roles for supporting family caregivers, including Children, Youth, and Families, Long-Term Services and Supports, and Behavioral Health. The directors of each division approved a charter, establishing a new Family Caregiving Integration Team at DHHS to kick off in 2021. The new Integration Team will facilitate ongoing opportunities for DHHS divisions to collaborate on family caregiving issues and will develop a cross-sector strategy to strengthen family caregiving policies and programs. Each division will represent different perspectives and stakeholder groups, which is critical for developing a holistic family caregiving strategy across the age continuum.

Virginia's team sought to support family caregivers whose family members receive or may become eligible for Medicaid by strengthening the partnership between the Department of Medical Assistance Services (DMAS) and the Department for Aging and Rehabilitative Services (DARS). Staff from DMAS and DARS partnered to establish a cross-sector Virginia Family Caregiving Workgroup that includes all six Medicaid health plans in the state. During their first meeting in August 2019, the workgroup identified opportunities to support beneficiaries and family caregivers, including introducing the Medicaid plans to VirginiaNavigator,¹² a statewide online database for disability, aging, family caregiving, and veteran services. The plans intend to train care coordinators to use VirginiaNavigator and offer the resource to members and family caregivers. The members of the Virginia Family Caregiving Workgroup acknowledge the value of their shared commitment and ongoing partnership, and plan to continue collaborating through the workgroup.

South Carolina's team initially sought to uncover strengths and gaps in public and private family caregiving programs across the state. In doing so, the South Carolina Department of Health and Human Services (SCDHHS) identified many agencies and organizations supporting family caregiving but operating in isolation. Thus, SCDHHS sought to increase communication and collaborate with the state unit on aging, the South Carolina Department on Aging, as well as private sector organizations, inviting the state chapters of the Alzheimer's Association and AARP and South Carolina Institute of Medicine and Public Health to participate on a team created to strengthen statewide family caregiving supports.

ELEMENT 2: Identify Leadership Champions

Cross-sector teams are strengthened through the support of committed state leaders, whose dedication can create the political will to elevate family caregiving as a state priority and encourage collaboration. States that were able to secure buy-in from legislative or executive-level leadership reported a clear relationship between success in this area and leadership support. Momentum across states was most noticeable and consistent when state leadership was engaged on this issue, which led to more progress among staff to then drive the work forward.

Furthermore, several states recognized that family caregiving is an issue that can bridge various political affiliations, agencies, or organizations across different social and economic environments. Because family caregiving is a familiar activity that spans all populations, states found that leadership champions emerged from diverse sources, with champions

"It was a proud moment to say this was important [to our team] and bring it to the attention of that level of leadership."

- New Hampshire Family Caregiving Team Member

often sharing personal stories and examples of how they have been affected by caring for a loved one. In the wake of the COVID-19 pandemic, these personal stories are becoming even more common and complicated as families across the country grapple with how to best provide care with limited access to fundamental services.

In terms of cultivating state champions, states suggest raising the importance of supporting family caregivers with a variety of stakeholders. Often, once this issue is raised, personal stories and experiences soon follow, resulting in potential champions to help elevate the issue and partner with on the work. For example, the New Hampshire team had an informal encounter with a state senator and were able to share their goals and work around this project and were encouraged by the senator offering support. They shared, "it was a proud moment to say this was important [to our team] and bring it to the attention of that level of leadership."

STATE EXAMPLES: IDENTIFY LEADERSHIP CHAMPIONS

Alabama's team was supported by both the Governor¹³ and the Speaker of the House, due to their personal experiences with family caregiving. Securing this level of leadership support accelerated the team's work and elevated interest around the issue, leading to a scheduled meeting with state legislators in March 2020 to discuss plans for a respite care training pilot at a local community college. Although the meeting was cancelled due to COVID-19, the leadership support is evident by continued interest in the topic and a commitment to revisit during the next legislative session in 2021.

<u>New Hampshire's team</u> recognized the need for leadership support and prioritized a series of meetings with division directors to communicate the value in supporting family caregivers. As a result, division directors at the Department of Health and Human Services offered strong support to the project team, demonstrating their commitment to prioritizing family caregiving. The team was able to secure their charter and establish the Integration Team at an accelerated pace due to executive leadership buy-in.



ELEMENT 3: Collaborate on Shared Goals

Establishing and maintaining a high-level goal is an important element of successful cross-sector efforts to improve family caregiving policies and supports. Most of the participating states chose one or two meaningful, achievable goals to focus on within their multi-stakeholder efforts (see Exhibit 1, page 4). Many acknowledged that family caregiving is a complex issue that spans many different areas of public policy, stakeholders, organizations, funding streams, and community needs, and that delving into one aspect often leads to uncovering other issues that need to be addressed. For example, a state focused on improving data analytic capabilities may realize that several agencies need to bolster data collection infrastructure to achieve their goal, or a state may find that expanding a family caregiver support program in one organization can create duplication within another. For states in the learning collaborative, remaining committed to one main goal helped them to stay on track and focus efforts even while addressing issues that inevitably arose.

State strategies for staying focused and establishing accountability included having clear roles and responsibilities across stakeholders, staying in close communication, and developing a detailed work plan. States also reported that bringing all entities together around a common goal allowed long-established silos to be broken down, and they could better identify overlaps and gaps in existing work, programs, and policies. Alabama's team, for example, established a goal to improve access to respite care by bolstering its direct care "[State government should] recognize the value of family caregivers — physically, mentally, and emotionally — and how that impacts someone's life, their community, and expectations about quality of life."

- Alabama Family Caregiving Team Member

workforce through the development of consistent training requirements and standards, thus increasing access for family caregivers, particularly in rural areas. Iowa's team committed to developing a standardized family caregiver assessment to be used by all AAAs, allowing for more robust and consistent data collection.

In developing shared goals, some states examined where programs could be reorganized to achieve them. One way to do this is to attach family caregiving to broader state reform activities, such as efforts to expand access to Medicaid long-term services and supports. For example, all states are facing direct care workforce shortages, and this shortage is expected to worsen over time as the population grows older and in the near term as COVID-19 persists. Furthermore, the workforce shortage coupled with the reluctance to invite outsiders into older adults' homes because of potential COVID-19 exposure, means that more care responsibilities are being taken on by family caregivers. All partners involved in Alabama's efforts recognized this and were focused on improving workforce access through their different programs, particularly in rural areas. The Alabama team established their goal to address both the workforce shortage and increase access to reliable, high-quality respite care for family caregivers. In Iowa, identifying that each AAA had their own processes for service delivery to family caregivers led to the development of a standardized assessment tool and protocols statewide. Inconsistent service delivery was revealed through significant gaps in the data. Standardizing the assessment and the intake processes made each AAA more efficient and helped Iowa reach their goal of more consistent service delivery and reliable data.

COVID-19 is testing states' ability to maintain program goals as they navigate new terrain and struggle to support family caregivers and vulnerable individuals amid increased safety precautions, service disruptions, and a sudden loss of formal paid caregivers. The pandemic is putting a variety of strains on family caregivers, such as social isolation, potential burnout from suspended external supports, lack of internet access or comfort with technology (e.g., telehealth), and limited interactions with health care facilities.¹⁴ In response to the pandemic, many states have implemented Medicaid flexibilities to support family caregivers, such as using certain available provisions in Appendix K for Home- and Community-Based 1915 (c) waivers. ¹⁵ Some states, like New Hampshire, are doubling down on efforts to strengthen family caregiver supports. As noted earlier, the state recently established its multi-stakeholder Family Caregiver Integration Team and is now redirecting action steps it planned with this group before the pandemic to develop aligned policies that address heightened family caregiver needs amid COVID-19. More than ever, it is crucial to think about the range of needs that family caregivers may have to offer the most effective support. As one Alabama team member noted, "[state government should] recognize the value of family caregivers — physically, mentally, and emotionally — and how that impacts someone's life, their community, and expectations about quality of life."

STATE EXAMPLES: COLLABORATE ON SHARED GOALS



Idaho's team, the Idaho Commission on Aging, Idaho Caregiver Alliance, the Division of Medicaid, and Area V Agency on Aging set a goal to expand service reach to more family caregivers by developing new contract requirements with Medicaid managed care plans. After further discussions with Medicaid staff, they maintained their goal to expand access, but redirected efforts to focus on outreach and care coordination for family caregivers. Idaho Medicaid (with funds from Idaho Home Choice, Idaho's Money Follows the Person program) accepted a proposal for the two-year Family Caregiver Navigation Pilot, launched in September 2020. The pilot is implementing an evidence-based family caregiver assessment tool and regional assistance database — involving AAAs, the Idaho Caregiver Alliance, Idaho 211 Careline, Idaho Parents Unlimited, Living Independence Network, large health systems, primary care providers, and other stakeholders. Participation in the pilot is open to any adult in southwest Idaho who provides unpaid care for another individual of any age with physical, intellectual, or cognitive disabilities or health diagnoses. The Navigator Pilot will create a person-centered action plan based on the family caregiver's needs and connect them with resources.

South Carolina's team recognized early on that several efforts regarding family caregiving were happening simultaneously, sometimes with overlap and similar priorities. To accelerate progress together, the team set their sights on one collective goal of identifying more effective strategies for reaching family caregivers, especially in rural and vulnerable communities. For example, the team explored creative solutions for reaching family caregivers, such as by distributing information at public libraries and partnering with faith-based organizations with a deep reach in the community. By committing to one goal, the team could channel their energy and collective expertise into that chosen area, as opposed to getting distracted by other organizational priorities.

ELEMENT 4: Establish Robust Data Collection and Exchange

Although robust data collection and information exchange are critical for effectively administering family caregiving programs, the process of collecting, assessing, and integrating data can be challenging for states. States need data to illustrate the important role that family caregivers can play in keeping individuals healthy and reducing the need for unnecessary acute service utilization and institutional stays. As an Alabama team member mentioned, "there is a lot of money saved because of the work done by family caregivers. If people recognize how much unpaid work family caregivers do, and how much it eventually saves different agencies — including Medicaid — it will help demonstrate the benefits of family caregiver supports and the need to expand them."

Consistent and effective data collection and analysis requires infrastructure, resources, and staff that states may lack. Furthermore, there is a need for meaningful data detailing family caregiver demographics and activities. Several states reported deficiencies in key data needed to identify family caregivers. Without the ability to identify family caregivers who might need services, where they are located, and what supports are being used, states cannot easily tailor programs to family caregivers' needs and address service gaps. As one Idaho team member shared, "systems need to continue to "Systems need to continue to recognize the contributions of family caregivers and the important role they play in each state's health care system. Without family caregivers, the systems would be unsustainable. And yet, family caregivers are often still invisible."

- Idaho Family Caregiving Team Member

recognize the contributions of family caregivers and the important role they play in each state's health care system. Without family caregivers, the systems would be unsustainable. And yet, family caregivers are often still invisible."

States, however, are beginning to make progress in developing strategies to collect and analyze family caregiving-related data. For example, South Carolina identified several key data points to better understand the universe of family caregivers who might need services and supports. The state tracks the number of family caregivers being served by AAAs, the types of services being used (respite care, adult day services, etc.), and the ways in which the agencies connect family caregivers to supplemental services, such as counseling. Meanwhile, a number of state participants leverage relationships with external partners, such as AARP, to gain access to national data, while others tap state universities to administer surveys and analyze data.

In addition to data collection, cross-stakeholder information sharing is another key element of program administration. With numerous stakeholders, such as AAAs, community organizations, state agencies, health plans, and others providing family caregiving services and supports at the state and community-level, designing a process for sharing clear, accessible, and pertinent information across programs is critical. Family caregivers are often unaware of the resources available to them despite best efforts by agencies and advocacy organizations to disseminate information. Some states, including Iowa and Virginia, are trying to build streamlined information systems that are accessible across agencies and stakeholders. This will hopefully allow family caregivers to receive optimal support and information.

lowa's team sought to gain a more holistic picture of the needs of family caregivers

STATE EXAMPLES: ESTABLISH ROBUST DATA COLLECTION AND EXCHANGE

through consistent processes and data collection across the state. In the past, the six state AAAs each administered an assessment with inconsistent questions and processes for collecting data, deterring aggregation at a statewide level. To streamline and identify strengths and gaps in the assessment process, the team held a continuous improvement event, attended by representatives from state agencies and all AAAs. During that three-day event, AAA and state aging staff clarified a definition of a family caregiver, explored the steps a family caregiver goes through when accessing AAA services, and developed targeted assessment questions to ask family caregivers that best reflected their experiences and needs. They examined existing assessments, identified where processes could be streamlined — including how and when family caregivers were assessed — and how to best connect family caregivers to resources. Together, the state's aging staff, AAAs, and Iowa's team implemented the assessment and protocols to capture the family caregiver voice, and in January 2020, began collecting consistent, meaningful data across the state's AAAs.

<u>Virginia's team</u> partnered with Virginia Commonwealth University in June 2020 to survey family caregivers to better understand the scope of caregiving activities, the amount of time they are providing care, and the challenges they face in their role. They plan to use this information to support the design of training, program, and education opportunities.

Looking to the Future

ow more than ever, states are actively prioritizing family caregiving. Driven by a growing aging population and, most recently, a global pandemic that has highlighted the dire need to support families struggling to care for high-risk loved ones, states are thinking creatively about how to build capacity and collaborate across multiple parties to expand the reach of these efforts. In an unprecedented time that is fraught with challenges, states are looking to the future and exploring innovative strategies for change.

However, in the months and years ahead, to achieve lasting change for family caregivers, states need buy-in and support in prioritizing family caregiving across legislatures and executive agency leadership. Having committed leadership champions throughout state government keeps the issue at the forefront and builds the necessary momentum needed to make lasting change. States recommend identifying the champions and leaders who are committed to supporting family caregivers and work to build a relationship early on.

The importance of breaking down silos and working in partnership is of paramount importance to this work. States reported their desire to continue to collaborate across state agencies and community organizations, knowing how much more can be done in partnership versus individually. Furthermore, the collaboration does not have to stop within a state — several states shared how invaluable it is to learn from other states that are grappling with the same challenges,

and recommended trying to find opportunities to connect across state lines. The six states highlighted in this brief have forged a path ahead in making incremental progress toward improving family caregiving services and supports in their communities. Continuing to build and strengthen partnerships across state agencies, community organizations, the private sector, and the family caregiver community will ensure a much-needed robust support system for family caregivers moving forward.

ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a nonprofit policy center dedicated to improving the health of low-income Americans. It works with state and federal agencies, health plans, providers, and community-based organizations to develop innovative programs that better serve people with complex and high-cost health care needs. For more information, visit **www.chcs.org**.

ENDNOTES

¹ National Alliance for Caregiving and AARP. "Caregiving in the US 2020." Available at: <u>https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316 ExecSum CaregivingintheUS WEB.pdf</u>.

² For purposes of this brief, family caregiving is defined as the act of an adult providing unpaid, consistent care to an older adult (age 50 or older) by assisting with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). ADLs include basic personal tasks, such as bathing, dressing, toileting, and eating. IADLs include common household tasks such as housework, shopping, banking/finances, and medication management.

³ "Supporting the Critical Role of Family Caregivers: State Opportunities." Center for Health Care Strategies, August 2019. Available at: <u>https://www.chcs.org/media/Family-Caregiver-Fact-Sheet 081519.pdf</u>.

⁴ Ibid.

⁵ Ibid.

⁶ National Alliance for Caregiving and AARP, op. cit.

⁷ AARP. "Home Alone Revisited. Family Caregivers Providing Complex Care." April 2019. Available at: https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf.

⁸ National Alliance for Caregiving and AARP, op. cit.

⁹ Ibid.

¹⁰ Ibid.

¹¹National Academies of Sciences, Engineering, and Medicine. *Families Caring for an Aging America*. 2016. Washington, DC: The National Academies Press. Available at: <u>https://nam.edu/families-caring-for-an-aging-america/#:~:text=The%20resulting%20report%2C%20Families%20Caring,%2C%20and%20overall%20well%2Dbeing</u>.

¹² VirginiaNavigator's mission is to provide helpful, free resource information associated with aging, disabilities, post-military life, and overall well-being. Learn more at: <u>https://virginianavigator.org/</u>.

¹³ "Governor Ivey Announces Alabama Team Picked for Learning Lab on Helping Family Caregivers of Older Adults." Press release, Office of the Governor, State of Alabama. November 2018. Available at: <u>https://governor.alabama.gov/newsroom/2018/11/governor-ivey-announces-alabama-team-picked-for-learning-lab-on-helping-family-caregivers-of-older-adults/</u>.

¹⁴ "Supporting Family Caregivers in the Time of COVID-19: State Strategies." Center for Health Care Strategies, June 2020. Available at: <u>https://www.chcs.org/supporting-family-caregivers-in-the-time-of-covid-19-state-strategies/</u>.

¹⁵ "Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers." Centers for Medicare & Medicaid Services. Available at: <u>https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html.</u>