



LTSS CHOICES

## Respite Services: A Critical Support for Family Caregivers

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### About this Series

*This Spotlight is part of the AARP Public Policy Institute's LTSS Choices initiative. This initiative includes a series of reports, blogs, videos, podcasts, and virtual convenings that seeks to spark ideas for immediate, intermediate, and long-term options for transforming long-term services and supports (LTSS). We will explore a growing list of innovative models and evidence-based solutions—at both the national and international levels—to achieve system-wide LTSS reform.*

*We recognize the importance of collaborating and partnering with others across the array of sectors, disciplines, and diverse populations to truly transform and modernize the LTSS system. We invite new ideas and look forward to opportunities for collaboration.*

**For all questions and inquiries, please contact Susan at [LTSSChoices@aarp.org](mailto:LTSSChoices@aarp.org).**

### Introduction

Family caregivers are a mainstay for long-term services and supports (LTSS) in the United States. More than 48 million people in the US provide care to parents, spouses, friends, and other people in their lives. In 2021, family caregivers provided about \$600 billion worth of care—a figure larger than all LTSS spending in the United States (\$400 billion) that same year.

The federal Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act<sup>1</sup> defines a family caregiver as “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.” Family caregivers generally help their care recipients without pay.

Generally, people with disabilities can remain more independent and stay in their homes longer if they have family caregivers available. Often, these caregivers provide help with a range of daily and household activities, medical tasks and

<sup>1</sup> The 2018 RAISE Family Caregivers Act directs the Secretary of Health and Human Services to develop a national family caregiving strategy to recognize and support family caregivers. Strategies include person- and family-centered health and LTSS care; assessment and service planning; caregiver information, education, training supports, referral, and care coordination; respite options; and financial security and workplace issues.

coordination, transportation, financial management, and advocacy.<sup>2</sup> For the most part, caregivers have little training on carrying out these tasks.

While the role may help family caregivers feel satisfied and give them more meaning in their lives, they also face challenges. Caregivers can feel stressed, overwhelmed, and lonely. They may also have physical and financial stressors related to taking care of children, keeping up with their jobs, and managing finances.<sup>3</sup> Some care recipients, especially those with cognitive impairment or dementia, need a caregiver to be on call 24 hours a day. Family caregivers may be in poor emotional or physical health themselves.

Family caregivers could benefit from a range of services that are tailored to their needs. These services could range from assistance with cleaning and meals to training for medically related tasks. Many family caregivers need respite care—that is, short breaks from their responsibilities.

This paper focuses on respite care and how it fits into the larger set of services that family caregivers need. This paper:

- provides a profile of family caregivers and their experiences;
- explores respite, its impact on family caregivers, and barriers to its use;
- describes federal and state programs that provide respite, including some examples of innovative programs;
- recommends improvements in respite research and programs; and
- describes how some respite programs are being scaled up.

In addition, this paper:

- summarizes available information<sup>4</sup> on family caregivers and respite because of the important role caregivers play in the LTSS system and the potential respite has in helping them with their responsibilities; and
- provides examples of innovative respite programs that policymakers may find useful.

## **Profile of caregivers**

In 2020, there were about 48 million family caregivers in the United States.<sup>5</sup> These caregivers provided an average of 18 hours of care per week.

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<sup>2</sup>Basic daily activities like eating, bathing, and dressing; medically related tasks like managing medications or cleaning wounds, often with little training; household tasks like cooking, cleaning, and shopping; coordination of outside medical care and LTSS; transportation to medical and social appointments; financial management like paying bills and managing bank accounts; and advocacy during medical and financial challenges, including insurance matters, Medicaid eligibility and services, and end-of-life care.

<sup>3</sup>Medicare doesn't cover many services for family caregivers. While Medicaid does cover the services, a recipient must have few financial assets and a low income to participate in this program. So people with disabilities and their caregivers often must pay for nonmedical services such as LTSS.

<sup>4</sup>References to many reports are in this document. The paper doesn't attempt to summarize all of the information in each report, so the authors encourage exploring these reports for additional information.

<sup>5</sup>Susan Reinhard, Selena Caldera, Ari Houser, and Rita Choula. "Valuing the Invaluable: 2023 Update Strengthening Supports for Family Caregivers," AARP Public Policy Institute, March 2023.

Caregivers of adults ages 50 and older are diverse.<sup>6</sup>

- 61 percent are white and not Hispanic.
- 17 percent are Hispanic/Latino.
- 14 percent are Black/African American.
- 5 percent are Asian American or Pacific Islander.
- 61 percent are women.
- 62 percent work at jobs while providing care.

Family caregiving experiences can vary by race and ethnicity.<sup>7</sup> For example, compared with caregivers of other races, more Black/African American caregivers provide care with no other help. Hispanic/Latino caregivers more often have children under age 18 still at home. Asian American caregivers more often have help from other unpaid caregivers. American Indian and Alaska Native family caregivers often feel reward and satisfaction from caregiving that is attributed to cultural respect for older adults and collective responsibility for their care.

LGBTQ family caregivers and their care recipients have different experiences.<sup>8</sup> Often these groups feel marginalized, excluded, and discriminated against in health care and LTSS. These family caregivers often feel isolated and have much emotional stress due to their caregiving responsibilities. They report worse health than other family caregivers.

The COVID-19 pandemic piled even more stress on family caregivers. The Global Carer Well-Being Index study surveyed 9,000 unpaid family caregivers in 12 countries.<sup>9</sup> Twenty percent of family caregivers reported that COVID-19 had forced them to take on caregiving responsibilities for the first time. Thirty-nine percent of family caregivers reported that care recipients relied on them more than ever for help.

The demographic diversity of family caregivers and their experiences points to the need for the LTSS system to take into account their varying needs and choices. Respite programs that don't do this are less likely to be able to help their participants.

### **Respite services and their impact**

Respite is most often defined as care provided to a person with disabilities so that their family caregiver can get a short break from their care responsibilities. More than a third of family caregivers want respite services. Yet only 14 percent of caregivers receive respite, according to AARP and the National Alliance for Caregiving's 2020 report on the results of a nationally representative survey of 1,392 adult family caregivers.<sup>10</sup> However, 38 percent felt respite services would help them.

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<sup>6</sup>AARP and National Alliance for Caregiving, "2020 Companion Report Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+," November 2020.

<sup>7</sup>Reinhard et al., "Valuing the Invaluable."

<sup>8</sup>Reinhard et al., "Valuing the Invaluable."

<sup>9</sup>Global Carer Well-Being Index, "Who Cares for Carers? Perspectives on COVID-19 and Lack of Support," June 2022, [https://www.embracingcarers.com/wp-content/uploads/Global-Carer-Well-Being-Index-Report\\_FINAL.pdf](https://www.embracingcarers.com/wp-content/uploads/Global-Carer-Well-Being-Index-Report_FINAL.pdf) as reported in "The Impact of COVID-19 on Carers: An International Perspective," International Alliance of Carer Organizations, June 2022.

<sup>10</sup>AARP and National Alliance for Caregiving, "Caregiving in the U.S."

Both percentages were higher among family caregivers who had more responsibilities. Examples include people who helped care recipients with cognitive or mental health problems or intense care needs. Caregivers who had cared for a recipient for at least five years, worked outside the home, or were lonely also were more likely to want respite services.

Although respite programs occur in a range of settings (including in a facility), this paper focuses on two strategies to provide short breaks for unpaid family caregivers where the care occurs in the home or an adult day services center.<sup>11</sup>

Evidence shows that respite services are helpful to family caregivers, including those who care for people with dementia. The clearest evidence of benefit exists for respite in adult day service centers because more research on respite outcomes has been conducted using this model. **See Appendix A for findings from our literature review and recommendations from prior research on the topic.**

### Factors affecting use of respite

Most of the research on factors affecting use of respite services focuses on caregivers of people with dementia. This section's discussion comes from three systematic reviews of the literature related to the impact of respite on family caregivers of people with dementia.<sup>12</sup> The review findings tend to overlap, so they are discussed together. The following factors, although specific to family caregivers of people with dementia, likely are similar to those that other family caregivers face. **See Appendix B for more information.**

1. **A person's background and values** affect family caregiver acceptance of respite, so programs need to be flexible to meet the caregiver's reality.
2. **Caregivers with higher levels of responsibility or for longer periods of time** are more likely to use respite.
3. **Communication** can affect respite use.
4. **Respite design**, particularly flexibility, can affect use of the service. Tailoring services to the needs of family caregivers and the person with dementia is the key to good design.

The lessons from this research are that tailored communications, flexible and accessible services, and trained staff delivering high-quality care are important. A respite program that takes this into account will be better able to meet the needs of family caregivers and their care recipients.

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<sup>11</sup> According to the Administration for Community Living (n.d.), two types of adult day services exist. "Adult social day care provides social activities, meals, recreation, and some health-related services. Adult day health care offers intensive health, therapeutic, and social services for individuals with serious medical conditions and those at risk of requiring nursing home care. Older adults generally participate on a scheduled basis." See [https://eldercare.acl.gov/public/resources/factsheets/adult\\_day\\_care.aspx](https://eldercare.acl.gov/public/resources/factsheets/adult_day_care.aspx) for more information.

<sup>12</sup> Marie-Conception Leocadie, Marie-Hélène Roy, and Monique Rothan-Tondeur, "Barriers and Enablers in the Use of Respite Interventions by Caregivers of People with Dementia: An Integrative Review," *Archives of Public Health* 76 (2018): 1–11; Emma O. Shea, Suzanne Timmons, Eamon O. Shea, Siobhan Fox, and Kate Irving. "Key Stakeholders' Experiences of Respite Services for People with Dementia and Their Perspectives on Respite Service Development: A Qualitative Systematic Review," *BMC Geriatrics* 17, no. 1 (2017): 1–14; Christine Neville, Elizabeth Beattie, Elaine Fielding, and Margaret MacAndrew, "Literature Review: Use of Respite by Carers of People with Dementia," *Health & Social Care in the Community* 23, no. 1 (2015): 51–63.

## Respite programs in the United States

Family caregivers have the potential to get respite from their responsibilities through several federal programs, which states often help manage. Respite is one of the services available to family caregivers in the following government programs; conditions for receiving respite vary:

- Medicare
- Medicaid
- Veterans programs
- Other federal programs that support respite and family caregivers, including the Lifespan Respite Care Program and the National Family Caregiver Support Program
- State-funded programs

The federal government oversees Medicare and the Department of Veterans Affairs programs. States manage Medicaid and other smaller programs under broad federal guidelines.

### **Medicare**

Medicare participants may receive respite care as part of Medicare's hospice benefit. In addition, some Medicare Advantage plans offer additional services to enrollees through certain supplemental benefits.

#### **Medicare Part A hospice**

- Medicare covers hospice care through Part A for people who are expected to live six months or less and agree to forgo efforts to cure the disease that is likely to cause their death. Many services are available under hospice, including physician care, medications, nursing and aide services, pain management, and respite.
- Medicare hospice-related respite gives family caregivers a break by temporarily covering the care recipient's stay in a Medicare-approved facility (such as a hospice inpatient facility, hospital, or nursing home). The hospice patient can stay up to five days each time the family caregiver gets respite. This inpatient respite is available more than once, but only on an occasional basis. The patient's copay is 5 percent of the Medicare-approved amount but can't exceed the inpatient hospital deductible for the year.<sup>13</sup>

### **Medicare Advantage**

Some Medicare Advantage plans began to offer expanded respite benefits in 2018, when the Medicare program first relaxed its rules related to Medicare Advantage Plan benefits. These plans could begin to offer special supplemental benefits to their members with chronic illnesses. Plans can choose to cover services like companion care; in-home services; respite care and counseling; and food, nonmedical transportation, pest control, and rent subsidies. Notably, these benefits do not necessarily provide comprehensive respite coverage to all plan enrollees. Plans have discretion on whether to offer supplemental benefits at all and, when they do, to determine which enrollees receive the benefits and with what limitations. As a result, these benefits could be very narrow and/or offered to only a small subset of enrollees.

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<sup>13</sup>"Hospice Care," Medicare.gov, <https://www.medicare.gov/coverage/hospice-care>.

The number of plans providing respite-related services has increased rapidly, except for adult day health services, which have decreased.<sup>14</sup> However, only a minority of Medicare Advantage plans are providing these services.

Following are some of the major categories of Medicare Advantage supplemental benefits related to respite, along with the number of Medicare Advantage plans offering each category of service. Note that there are about 4,000 Medicare Advantage plans in 2023<sup>15</sup> and that plans offering these benefits do not need to provide them to all enrollees.

- **In-home supports** are services that help Advantage plan members with disabilities or medical conditions to carry out daily activities in their homes to compensate for physical problems. The number of Medicare Advantage plans offering in-home supports rose from 223 in plan year 2020 to 1,091 in plan year 2023.
- **Adult day health services** provide care outside the home, such as help with daily activities, education to help the plan member do daily activities, physical maintenance or rehabilitation activities, and social work services. The number of Medicare Advantage plans offering adult day health services declined from 84 in plan year 2020 to 41 in plan year 2023. This decline was likely due to the restrictions of the first few years of the COVID-19 pandemic.
- **Support for caregivers of plan members** includes respite care, which is provided by a personal care attendant or in an institution for a short period. The number of Medicare Advantage plans offering support for caregivers rose from 125 in plan year 2020 to 293 in plan year 2023. Other services are available through this benefit, such as caregiver education.

Measuring the impact of these Medicare Advantage supplemental benefits on enrollees can be difficult. One reason is that finding a control or comparison group often isn't possible.<sup>16</sup> Among the reasons are that plan members who have similar needs must get similar benefits, and plans have varying benefits, clinical models, provider networks, and other factors that can affect enrollees' outcomes. Another challenge is knowing the characteristics of the people who use these supplemental benefits.

In addition to the supplemental benefits program, Medicare Advantage is also testing an innovation model that integrates the Part A hospice benefit with Medicare Advantage through the Hospice Benefit Component of the Value-Based Insurance Design Model. This is a relatively new innovation model taking place in parts or all of more than 20 states through 15 Medicare Advantage plans as of 2023. Limited findings specific to respite are available, and future evaluations of the VBID model should increase understanding of the hospice component's implementation and impact.

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<sup>14</sup> "2023 Expanded Primarily Health-Related Benefits in Medicare Advantage," ATI Advisory, October 11, 2022.

<sup>15</sup> Meredith Freed, Jeannie Fuglesten, Anthony Damico, and Tricia Neuman, "Medicare Advantage 2023 Spotlight: First Look," Kaiser Family Foundation, November 10, 2022.

<sup>16</sup> Alison Rizer and Laura Benzing, "Filling the Gaps: The Role And Value of Supplemental Benefits In Medicare Advantage," *Health Affairs Forefront*, August 5, 2022.

## Medicaid

Medicaid defines respite as intermittent or regularly scheduled temporary medical care and/or supervision of the participant.<sup>17</sup> Respite typically includes support to help the participant live at home, protect the person's safety through care and supervision when a family member isn't available, and provide relief to the family caregiver.

Medicaid has many options for providing respite services through various waivers of traditional Medicaid rules.<sup>18</sup> These options include research, demonstration, and waiver programs under Medicaid that allow states to provide respite as one of their home and community-based (HCBS) services. These include 1915(c) HCBS waivers, 1915(b) managed care waivers, and 1115 research and demonstration project waivers. The types of respite services that Medicaid waivers can offer include in-home respite services as well as those in a community setting (e.g., in an adult day services center) or inpatient setting (e.g., a licensed residential facility).<sup>19</sup> Other Medicaid waiver services that can offer respite to family caregivers are companion services, personal care, attendant care, medical day care, and adult day care.

Under many HCBS waivers, states can offer Structured Family Caregiving services, which help family caregivers of Medicaid participants with disabilities. Help can include payment of family caregivers, individualized training, coaching, respite care, and other supports. Home health agencies generally manage the services for the state. This program is an alternative for those Medicaid participants who cannot self-direct services. In August 2022, at least seven states (Connecticut, Georgia, Indiana, Louisiana, Missouri, North Carolina, and South Dakota) provided these services to family caregivers who are the primary caregivers to the participant and live in the home with them.<sup>20</sup>

Most state Medicaid waivers cover respite care and adult day services for older adults and adults with physical disabilities. However, respite and adult day services often are tiny percentages of 1915(c) waiver budget estimates.<sup>21</sup> The median percentage of 1915(c) waiver funding for respite care is 0.49 percent and for adult day services is 1.05 percent.

### Respite and the *LTSS State Scorecard*

The *2023 LTSS State Scorecard* for the first time includes an indicator specific to respite services, measuring how state Medicaid HCBS waiver programs provide access to respite. We found that most states have a respite benefit written into their HCBS waivers for older adults and/or people with physical disabilities. For more information, visit: <https://ltsschoices.aarp.org/scorecard-report/2023/dimensions-and-indicators/respite-care-through-medicaid-waivers>.

<sup>17</sup>Vivian Gabor, "Federal Funding and Support Opportunities for Respite Building Blocks for Lifespan Respite Systems," ARCH National Respite Network and Resource Center, 2020. University of South Carolina Institute for Families in Society, "Medicaid Waivers for Respite Support State-by-State Summaries of Medicaid Waiver Information," ARCH National Respite Network and Resource Center, 2019.

<sup>18</sup>Gabor, "Federal Funding and Support Opportunities."

<sup>19</sup>Gabor, "Federal Funding and Support Opportunities."

<sup>20</sup>Neva Kaye, "Medicaid Structured Family Caregiving: Enabling Family Members to Make Caregiving Their Primary Focus," National Academy for State Health Policy, 2022.

<sup>21</sup>Kimberly Hodges, "State Respite Care Spending Is Low in Most Home and Community-Based 1915(c) Waivers," National Academy for State Health Policy, 2022.

Medicaid also has several state optional services that pay for personal care services, which can offer family caregivers a short break from their responsibilities. These options include the Medicaid personal care benefit, 1915(i) HCBS state plan options, and the 1915(j) self-directed personal assistance state plan option. Finally, 23 states use Medicaid Managed LTSS programs to serve older adults and adults with physical disabilities.<sup>22</sup> All of these programs provide respite and adult day services. Some of the states allow the managed care organizations to expand upon the required respite services.

### ***Veterans' programs***

The federal Department of Veterans Affairs (VA) offers direct services, budgets, and cash benefits that family caregivers can use for respite when they take care of a veteran with disabilities or are the surviving spouse of a veteran.

**Home respite care** is available for up to six hours at a time. A home health aide can go to a veteran's home, or the veteran can go to an adult day care program while their family caregiver takes a break or runs errands. This respite benefit is available for up to 30 days in a year.

**Cash benefits** can be used to hire workers who provide respite for primary family caregivers. However, these cash benefits generally pay for the main family caregiver's services. These programs include the following:

- **Veteran-directed Home and Community Based Care.** This program offers a flexible budget to veterans of all ages who are enrolled in the VA's medical benefits and who need help with daily activities. Respite care is one of the options veterans can purchase when choosing how to spend their benefit.
- **Aid & Attendance Pension Benefit.** Certain veterans and surviving spouses can get a cash benefit if they require in-home or facility-based care. Participants can buy respite services.
- **Housebound pension benefit.** This program is for veterans who have a permanent disability and are mostly unable to leave home. The veteran or surviving spouse can use this cash benefit to buy respite services.
- **Program of Comprehensive Assistance for Family Caregivers (PCAFC).** This monthly cash benefit initially went directly to family caregivers of veterans who were hurt and disabled in the line of duty after the terrorist attacks of September 11, 2001. Now veterans with certain levels of disability from all eras are eligible. They can receive more than 30 days of respite care a year.

### ***Other federal programs that support respite and family caregivers***

At least three other federal programs support the use of respite care for adults. Research on two of the programs—National Family Caregiver Support Program and the AmeriCorps Senior Companion Program—show that family caregivers benefit in many ways from participating in them.

- **The Lifespan Respite Care Program** provides federal funds to coordinate, expand, and improve community-based respite services, including those that receive funding from state and federal programs. These programs coordinate services for family caregivers regardless of the age or disability of the person who is receiving help.

<sup>22</sup> Kimberly Hodges, "States Cover Respite Care and Adult Day Services and Supports in Managed Long Term Services and Supports (MLTSS)," National Academy for State Health Policy, 2022.



State Lifespan Respite grantees have contributed to the ever-expanding examples of model respite services and strategies by enhancing respite access through innovative volunteer and faith-based respite services, implementing self-directed and person-centered respite voucher programs, increasing respite capacity by recruiting and training respite workers and volunteers, and developing statewide coordinated systems of respite care services in partnership with State Respite Coalitions and Aging and Disability Resource Centers/No Wrong Door systems that make it easier for family caregivers to understand and access respite services.

- **The National Family Caregiver Support Program (NFCSP)**, under the Older Americans Act, funds respite for certain family caregivers.<sup>23</sup> A 2018 evaluation of NFCSP included a survey of caregivers who received NFCSP services. Of those, 43 percent had received respite within the past six months. Participants used respite care more than education/training, individual counseling, and support group services combined. 86 percent of users said respite was very helpful and 42 percent said respite was the most helpful service they received. Those family caregivers who didn't use the program's respite care in the past six months reported their reasons. About one-third of caregivers said they didn't know about the service. Other reasons included that the caregiver didn't qualify for or need the service.
- **AmeriCorps Senior Companion Program** has volunteers ages 55 and older who provide respite for certain family caregivers of people who have difficulty carrying out daily activities. Research shows that family caregivers who receive these services report<sup>24</sup> less depression, stress, and time constraints as well as better social connections and physical and mental health.
- **The American Rescue Plan Act (ARPA)** increased the percentage of the federal government's contribution to Medicaid HCBS by 10 percentage points between April 1, 2021, and March 31, 2022.<sup>25</sup> Twelve of the states' initial plans for spending these funds included respite for family caregivers. Planned state respite improvements included increased funding to existing respite programs, payments to providers to increase respite capacity and training, and efforts to connect people to respite services. Thirty states had plans to support family caregivers more broadly.

Research from the National Family Caregiver Support Program and the Senior Companion Program shows that respite is one of the most requested caregiver support services and is a useful benefit for many family caregivers. The research also showed that communication about program benefits could be improved. However, not everyone needs respite. These results are compatible with the research results on the benefits of and barriers to respite.

<sup>23</sup>The eligible population of family caregivers served by the NFCSP are as follows:

- Adult family caregivers (age 18 and older) caring for an older adult with support needs (age 60+)
- Adult family caregivers (age 18 and older) caring for an individual of any age with dementia or related disorder
- Older relatives (not parents/age 55+) providing care to children under the age of 18
- Older relatives (including parents/age 55+) providing support to adults ages 18 to 59 with disabilities

<sup>24</sup>Anthony Nerino, "A Systematic Review of Senior Corps' Impact on Volunteers and Program Beneficiaries," (2019).

<sup>25</sup>National Academy for State Health Policy, "Map: ARPA Initial Plan Proposed Supports for Family Caregivers," November 22, 2021.

### State-funded respite programs

According to the Family Caregiver Alliance<sup>26</sup> and ARCH,<sup>27</sup> at least 11 states use state-only funds to cover respite. This service is generally one of a range of HCBS for populations that don't qualify for Medicaid. California, New York, and Rhode Island have state-funded programs, as described in section 8. Other states include the following:

- **Arizona's** Non-Medical Home and Community Based Services Program helps older adults remain at home with a wide range of services including adult day care and respite. Priority is given to older adults based on their functional and financial needs.
- **Connecticut's** statewide respite care program serves people with dementia.
- **Maine's** Respite for ME: Family Caregiver Grants Pilot Program provides \$2,000 grants to family caregivers of people living with Alzheimer's disease and related dementias. The grants allow family caregivers to access respite care as well as other services not currently covered by existing programs. A portion of the total funding supports evaluation of this pilot program.
- **Maryland's** statewide respite program serves caregivers of people of all ages and all disabilities.
- **Minnesota's** Alternative Care Program provides care to older adults with low incomes and assets who need nursing home level of care. This is a group that wants to live at home and doesn't yet qualify for Medicaid. A wide range of services is available including adult day services and respite.
- **Nebraska's** Lifespan Respite Care Program is completely state funded.
- **New Jersey's** program is similar to Minnesota's in terms of functional and financial eligibility and range of services available. Both state programs target people who are at risk of becoming eligible for Medicaid.
- **South Carolina's** respite voucher program is for people with Alzheimer's disease.

### Innovative respite programs

No single respite program has all the key elements that experts recommend, and only a few aspects of respite have been scaled up to some degree. However, some programs have implemented promising models and practices that others might want to consider adopting or learning about. These programs are in Alabama, California, New York, and Rhode Island.

There are other innovations related to learning collaboratives and under the Medicaid program.

#### Alabama

Montgomery, Alabama, is the birthplace of a wide-ranging faith-based respite program. First United Methodist Church's Respite Ministry for adults with memory loss began in 2012 with a startup fund of \$50,000 from the church.<sup>28</sup> A church member, Daphne Johnston, felt a call to the respite ministry; she had worked in the LTSS field and knew about the needs of family caregivers.

<sup>26</sup> "Family Caregiver Services by State," Family Caregiver Alliance, <https://www.caregiver.org/connecting-caregivers/services-by-state/>, accessed May 29, 2023.

<sup>27</sup> Personal communication from Jill Kagan, director of the ARCH National Respite Network and Resource Center, June 26, 2023.

<sup>28</sup> Mary Catherine Phillips, "First UMC's Respite Ministry Thriving in Caring for Those with Memory Loss," *Montgomery Advertiser*, April 11, 2017.

By 2017, the program was operating four days a week with 120 volunteers who spent 11,000 volunteer hours a year working with program participants. More than \$30,000 of scholarship money was awarded in 2016 for participants who couldn't afford the day program's rate.

The Respite Ministry offers adult day care with activities to engage participants. The activities are designed to help participants feel like they are coming each day to volunteer their services. Everyone wears a similar name tag, sits together, and participates in group activities.

The ministry accepts people with memory loss from outside its membership and has no quotas related to religious status. However, participants must be independent in these areas:

- Mobility, but use of mobility aids or wheelchairs is allowed
- Eating and toileting, but absorbent briefs are allowed
- Participating cooperatively in a group

### Respite in their Own Words...

#### Piper and Charlie (Alabama)

Piper and Charlie have been married 48 years. About five years ago, Piper began noticing that Charlie was forgetting things and not processing requests the way he had done in the past. He was not finishing thoughts, and he was forgetting words and names of places he had frequented for years. He eventually lost his retirement job, which he enjoyed, at a local hardware store because he couldn't carry out his responsibilities.

In 2018, when Charlie turned 75, he was diagnosed with dementia. Piper had to retire from her teaching job to take care of Charlie full time. She is in her early 70s.

After her retirement at the end of the school year, Piper and Charlie were with each other all the time. This was not working for either of them because Charlie was used to getting around on his own. However, this wasn't safe for him anymore; Piper always had to be with him.

A friend from the local Methodist church told Piper about the church's respite ministry, which involves adult day services. The school nurse where Piper had taught also told her about the program. Piper looked into it, and she and Charlie gave it a try.

Charlie now goes to the respite program four days a week. He and everyone else who goes there are friends, and all have the same kind of name tag so no one can tell who has dementia or is a staff person or volunteer. Charlie now can socialize and be with his friends. He has fun at the adult day program. They sing, do arts and crafts, and play games.

Piper gets time to herself to relax, do errands, use the bathroom in peace, and have lunch with friends. She says that she would not trade the adult day program for anything in this world. She believes the program enables her to keep her husband at home longer than she would have been able to do on her own.

Piper also gets help from a caregiver support group that the church runs and the PANDA project, to which the church connected her. The project is a nonprofit organization, affiliated with the Alabama Council on Aging, which helps families when a loved one has disabilities. They provide a variety of services, including some free equipment. Charlie has a robotic cat that he pets and interacts with.

**Respite in their Own Words....****Christine and Bob (Alabama)**

In early September 2017, Bob learned that his wife of 37 years had Alzheimer’s disease. They had visited their doctor because Christine had been forgetting things like how to drive home on familiar routes and manage her medications, and her short-term memory had begun suffering.

Bob has gradually taken on all the driving and managing Christine’s medications. Although they had always shared household tasks, Bob has done more of them as Christine’s dementia has progressed.

In 2018, when Bob and Christine were at her doctor’s office, Bob found a brochure about the respite ministry at an Alabama Methodist church. Bob called them right away and enrolled Christine in the adult day program.

Bob says that the respite program has enabled Christine to interact with others, have fun, and stay more engaged with life. She participates in music, singing, crafts, and exercises like balloon volleyball. Children from the church’s day care program visit, as do teenage choirs. Bob thinks that Christine would have declined faster if she hadn’t had the interactions with people in the respite program.

When Christine is at the respite program, Bob is able to do things like prepare her medications. He also says respite, along with the flexibility from his employer, enables him to keep his job and work more productively.

He calls the respite program a “gift from God.” He wishes more churches would create respite ministries because so many people would benefit from them.

People who are able pay \$40 a day in 2023, and scholarships are available for those who can’t afford it. The fee includes a hot lunch.

The ministry focuses on the abilities of its program participants, who are called “friends.” Friends are asked to do meaningful group work and engage in group creativity and play. Up to 30 friends (i.e., people with dementia) attend each day, along with 15 volunteers and one staff member at the First United Methodist Church in Montgomery. Participants may choose to come one or more days. All told, 75 friends and 100 active volunteers are involved at this church site. Volunteers at the adult day services often are church members. Activities include the following:

- Arts, including music, dance, and crafts
- Exercise
- Optional chapel services
- Intergenerational activities
- Pet therapy
- Service projects
- Care for the caregivers

Respite leaders created the Respite for All Foundation in 2018 with the goal of inspiring respite in other communities by providing support and training including best practices. The foundation has helped create new respite programs in 35 communities, with 1,700 trained and active volunteers along with 2,000 people living with dementia and their family caregivers who receive services. RFA is now in 13 states and growing.

According to the foundation, these communities are sustainable because space is available in the churches. Volunteers provide free service, so few paid staff are needed. No medical care is needed during the adult day services because this is a social model. Liability insurance is covered under the church's policies. The faith-based model attracts other community partners.

The main advantages of faith-based models are acceptability and availability in local communities and affordability for participants and their families. Alabama's faith-based model is scaling up by providing an example that other respite programs can follow.

The ARCH Respite Network points to other faith-based models in Texas and South Carolina.<sup>29</sup> The network has tools available to faith-based communities to help them create respite programs. Existing programs in Alabama, South Carolina, and Texas share information with interested parties.

ARCH has many other models of successful volunteer respite options that can be found in its Innovative and Exemplary Respite services database.<sup>30</sup> They also offer a Volunteer Respite Manual and a Roadmap to Volunteer Respite Services<sup>31</sup> that are available to agencies and faith-based communities to help them build or enhance new volunteer respite care services.

### **California<sup>32</sup>**

California's Caregiver Resource Center system has an impressive array of services for unpaid family caregivers; services include respite. This system meets many of the recommendations listed in section 7.

In 1984, California expanded support to unpaid family caregivers providing care to those with adult-onset cognitive impairments (for example, dementia, stroke, Parkinson's disease, and head injury) to 11 Caregiver Resource Centers. The Caregiver Resource Center system serves the entire state under the California Department on Aging.

Each center offers core programs that include the following:

- **Uniform caregiver assessment** to determine family caregiver needs and services resulting in an action/care plan. There is a reassessment at six months to determine care plan progress and need for additional services.
- **Specialized information** involving tailored advice, information, and assistance on caregiving issues and community resources.
- **Family consultation on care, planning, and emotional issues of caregiving; care navigation to local resources, health care services, and care options** that involve family caregivers meeting with trained staff who offer emotional support, connect caregivers with community resources, and increase family caregivers' understanding about care options.
- **Respite Care**, a consumer-directed voucher program providing care breaks using in-home, day care, day health care programs or short-term stays in facilities

<sup>29</sup> ARCH National Respite Network, "Respite and the Faith Community." n.d.

<sup>30</sup> The database is at <https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/#SearchlandE>.

<sup>31</sup> Innovative and Exemplary Respite Services database: <https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/#SearchlandE>; Volunteer Respite: Roadmap to Resources: <https://archrespite.org/library/volunteer-respite-valuable-resources-2;> Volunteer Manual: <https://archrespite.org/library/volunteer-respite-manual/>.

<sup>32</sup> Information in this section was provided via personal communication with Kathy Kelly, executive director of the Family Caregiver Alliance, on June 28, 2023.

- **Support groups led by trained center staff that meet regularly** for caregivers to share experiences and ideas about dealing with the stresses of caregiving.
- **Short-term counseling with licensed professionals** related to care, decision making, emotional support, and family dynamics.
- **Caregiver training and education**, which include classes for caregivers on stress management, self-care, dementia, and other topics. Community members and professionals can participate in some of the education programs.
- **Targeted caregiver interventions** that are evidence-based, such as Powerful Tools, PEARLS counseling protocol, and REACH for Spanish-speaking caregivers. Centers also test new interventions routinely.

Services are delivered by telehealth, in person, by telephone, or on digital platforms.

In fiscal year 2022, 2,080 caregivers received respite services for a total of 119,378 hours of care, or about 60 hours per caregiver on average. Respite is consumer directed using vouchers that best meet the values and preferences of the family and the person needing assistance. In some diverse communities and for those in rural areas, consumer-directed options may be the only way respite can be provided given cultural preferences or lack of formal care options in rural areas. The centers have care training materials and videos for those providing respite if needed as well as consultation from center staff on the best ways to maximize respite options, benefits, and additional respite if available.

All activities are tracked on a secure, client-facing, interactive record system (CareNav) that allows for all assessment data and service activities to be entered and exported for reporting (across funding sources); formal evaluation; and use by individual sites for their own quality assurance and planning needs.

### ***New York***

New York's State Office for the Aging administers and blends funds from several major respite programs for older adults:

- The National Family Caregiver Support Program and Lifespan Respite funded under the Older Americans Act
- A state-funded Expanded In-Home Services for the Elderly Program
- A state-funded respite program

A nonprofit coalition administers a fourth program under an AmeriCorps grant.

### **Expanded In-Home Services for the Elderly Program**

Respite is one of the supports offered through this program. Following are the criteria for eligibility:

Eligibility criteria includes the person being 60 years of age or older, needing help with at least one ADL or two IADLs and unmet need for this help, and not be eligible for similar services from another public program. Participants need to apply for Medicaid if it appears they may be eligible. The person must be able to live safely in their home environment and for noninstitutional respite, the person must have one or more family caregivers who provide continuing care.

For consumer-directed in-home services, the individual must meet all of these conditions and be capable of making choices regarding the services they want and managing their home care worker or be capable of delegating management to another person who can carry out the activities.

## State respite program

The Office on Aging distributes state respite funds to eight community-based agencies and two local offices for the aging that serve 30 counties in New York. The agencies include the Alzheimer's Association of Western New York, Catholic Charities, and various other community organizations.

To be eligible for the respite program the person must be a family or unpaid caregiver who cares for or supervises an adult who is frail or has disabilities. The caregiver doesn't have to live in the same home as the adult with disabilities. The adult must be unable to take care of their daily needs without help. People ages 60 and older are the target for services. Respite is limited to 100 days of care per person each year.

## Respite in their Own Words....

### Stephanie and Darren (New York)

Stephanie and Darren have been married about 20 years. It is the second marriage for both of them. They live near the Canadian border in upstate New York.

Darren has probably had Parkinson's disease and accompanying dementia for about five years. He finally received his correct diagnosis in 2021, after being treated incorrectly for seizures by a different neurologist. Darren now has to use a walker to get around his home, and he cannot stand by himself or go down the steps to get out of his home. Stephanie can't leave him alone.

Darren received his diagnosis in early 2021. Darren's neurologist then referred him and Stephanie to the Alzheimer's Association, which gave them some good information, including 10 phone numbers Stephanie could call to get some help in caring for Darren.

The local Office on Aging was the first group to return Stephanie's phone call. The program coordinator visited Darren and Stephanie in their home and set them up with helpful services, including these:

- Meals on Wheels five days a week for Darren. The meals are varied and delicious. Stephanie could ask for more of them but likes to cook for herself and her husband on weekends. The head of this program visited Darren and Stephanie in their home to talk with them about their situation and meal preferences.
- Legal aid
- Part-time home help in the form of respite twice a week for three hours each time.

Stephanie and Darren have had the same aide, whose name is Hope, ever since they began receiving services through the Office on Aging's programs. Hope makes all the difference to both of them. Hope is Darren's friend and treats him with dignity and respect. He lights up when she walks into the room. Hope helps him with bathing, dressing, and eating; does exercises with him; and does some light housework. Stephanie gets time to herself and knows that Darren is safe with Hope when Stephanie does errands or socializes with her family or friends. Stephanie would not be able to be social or do errands without the respite that Hope provides.

Stephanie says that she plans to keep Darren at home for as long as possible because she knows that Darren wouldn't last long in a nursing home, given what she's seen other people go through. Hope's presence in their lives helps make Stephanie's goal possible.

Stephanie said that the St. Lawrence County Office on Aging's program is responsive to her and Darren's needs and has adjusted services over time. The office staff's home visits are incredibly helpful since Darren isn't mobile. The office's program coordinator keeps in touch with Stephanie regularly by telephone, and other staff make periodic visits to make sure that Stephanie is getting the help she and Darren need.

### **AmeriCorps grant**

AmeriCorps, which is the federal agency for national service and volunteerism, gave the New York State Caregiving and Respite Coalition \$3 million to recruit and train 300 people ages 55 and older to provide respite for people caring for older adults and those with disabilities. People who provide respite with incomes below 400 percent of the federal poverty level will be eligible for two-year stipends to increase their incomes.

The grant's goals are to increase the respite workforce and help about half of the 300 people find nonsubsidized work providing respite and caregiving assistance. In each county, the coalition will partner with nonprofit organizations, faith communities, and government departments to recruit people ages 55 and older for the positions. The coalition and its parent organization, Lifespan of Greater Rochester, work closely with and receive funding from New York's State Office for the Aging and the federal Administration for Community Living.

### **Rhode Island<sup>33</sup>**

Another way of making respite more affordable is recruiting nursing students to provide services. The Rhode Island CareBreaks-Nursing Student Respite Workforce Initiative enables two-year and four-year nursing students to learn about and provide respite as part of their college coursework. The Rhode Island Office of Healthy Aging works with the colleges and universities to train and support nursing students.

CareBreaks matches low- to moderate-income families with student nurses who provide free respite care. The families benefit, the supply of respite providers increases, and students get experience delivering care.

The nursing schools incorporate respite into the nursing classes and match students with families that the state respite services coordinator—Catholic Social Services of Rhode Island—refers to the nursing school. Aging and Disability Resource Centers provide assistance to family caregivers and make them aware of CareBreaks.

Funding for CareBreaks comes from a Lifespan Respite grant, first awarded in 2014 and continued in 2017. These grants enabled four of the state's nursing schools to revise their curricula to educate nursing students about various types of disability among adults and children and person-centered care as well as build in opportunities for students to deliver respite. The schools separately focus on dementia care, disabilities among children, community health and the role of respite, and family members of all ages with disabilities. All four schools orient student nurses to respite and provide students the opportunity to deliver it for course credit.

CareBreaks has a toolkit that other educational institutions can use to replicate the program. ARCH recognizes this program as an innovative and exemplary respite service.

CareBreaks evaluated its respite service's quality for 169 students. Outcome data show that the nursing students increased their knowledge of and interest in respite. Students wished for more training before starting respite. Family caregivers said that respite provided them with a needed break from their responsibilities. The program's respite services relieved caregiver stress. However, caregivers disliked the amount of paperwork associated with getting the service.

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<sup>33</sup>Rhode Island Office of Healthy Aging, "Supporting Family Caregivers, Nursing Students as Respite Providers," July 2020.



**Medicaid waiver innovations<sup>34</sup>**

The National Academy for State Health Policy (NASHP) interviewed seven state Medicaid waiver program administrators. NASHP considers Iowa, Kentucky, Louisiana, Missouri, Texas, Virginia, and Washington to have particularly innovative respite programs. Their innovations fall into several categories, which are in line with the respite program recommendations described previously:

- **Education.** Administrators realize that Medicaid participants can't use respite if they don't know about it and its availability. Kentucky tackles outreach through its case managers who explain respite when participants enter the program. This state also asks outside organizations such as support groups and coalitions to educate their members about respite.
- **Types of respite.** Three of the seven states have more than one type of respite. For example, Missouri has basic respite and advanced respite. The latter is for people whose needs are complex, like those having behavioral symptoms of dementia, needing mechanical transfers from bed, or having trouble swallowing. Iowa has individual, group, and specialized respite.
- **Flexibility.** The states take two approaches to flexibility: (1) pooling respite funds in a self-directed program and (2) packaging respite and regular personal care together so that participants can use the same providers for both types of service.
- **Self-direction.** Under their self-direction programs, the states allow participants to employ agency staff, family, or friends as respite providers. This mitigates workforce shortages and gives participants confidence in the workers because they are people they know.
- **Managed care.** Study states use their Medicaid managed care plans to offer respite to enrollees. For example, plans can offer respite to the state's regular Medicaid program enrollees who aren't eligible for HCBS waiver services. Plans also can offer more respite than is available under the HCBS waivers.
- **Payment.** Forty-nine states use ARPA funds to increase payments for HCBS services, including respite. Virginia, Iowa, and Kentucky aim to make these rate increases permanent.

**Conclusions and policy considerations**

Family caregivers provide a broad range of services to their care recipients with various forms of physical and cognitive disabilities. Help ranges from transportation to assistance with basic daily activities like eating and bathing and medically related tasks. Many of these caregivers provide this assistance on their own or with very little help for years. About 40 percent of caregivers say that flexible respite, or short breaks away from daily care responsibilities, would be beneficial. And research indicates that caregivers who use respite have lower caregiver distress and better health and sense of well-being.

More research is needed to document the impact of respite on family caregivers and their care recipients. Among the improvements needed are consistent definitions of respite, study of respite as a distinct service, research on methods of ensuring quality, and studies of barriers to service use.

Research on barriers to family caregivers' use of respite indicates that affordability, inflexible program design, difficulty accessing services due to language and cultural differences, obscure procedures for applying for services, lack of targeting to the caregivers who need respite the most, a lack of trained respite providers, and inadequate quality assurance create difficulties for families.

<sup>34</sup> Kimberly Hodges, Ella Taggart, Neva Kaye, and Wendy Fox-Grage, "Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disability, and their Family Caregivers," National Academy for State Health Policy, May 2023.

Several federal and state programs provide access to respite for family caregivers, although many caregivers don't know about them. Medicaid is one of the major sources of funding through its home- and community-based services options. Most programs offer respite, but this service is generally a small part of their overall budgets. Medicare has limited respite services available through hospice and some Medicare Advantage plans. Again, respite spending is a small percentage of program expenditures. Veterans programs are more robust, and there are several options for veterans who have disabilities or receive medical services through the VA system. Programs that the Administration for Community Living (National Family Caregiver Support Program and Lifespan Respite) and AmeriCorps oversee provide respite. However, these programs' funds are capped. Finally, some states have invested their own funds into respite programs.

Several national reports have made recommendations for improving respite. These are listed below, with **more information on these recommendations in Appendix C.**

- using a broad and standardized definition of respite;
- assessing and regularly reassessing needs;
- focusing on the needs and choices of the family caregivers;
- addressing any trauma that caregivers face;
- addressing cultural expectations, differences within communities, effects of discrimination, and nontraditional families;
- ensuring that family caregivers know about the availability of respite in their communities and have easy access to the service;
- training and paying the professional workforce well to ensure high-quality services; and
- ensuring that respite is flexible and affordable.

No one state program encompasses all of these recommendations. However, some programs are very innovative as described in detail in section 8 of this paper. Several communities in Alabama have addressed affordability and scaling up through the voluntary sector. A church in Montgomery has sparked affordable adult day center respite services, which focus on people with dementia and their family caregivers using a social model. So far, this model exists in four states, with assistance from a church-based foundation in Alabama, Georgia, and South Carolina. The foundation provides education and information to sites in these states.

California's statewide Caregiver Resource Centers have been around since the mid-1980s. The centers screen people who call and assess family caregivers' needs initially and again after six months, if necessary, using a uniform tool. Respite is available along with other services, such as counseling, family caregiver training, and legal consultation. Services are available in multiple languages. This state has tackled most of the recommendations mentioned here.

New York State has blended several funding streams to provide respite care to its residents, including a state-funded respite program. Also within the state is a new multimillion-dollar grant from AmeriCorps to recruit older adults to provide respite.

Rhode Island has focused on expanding the pool of trained respite workers by working with nursing schools to give students experience working with people with disabilities and providing students with class credits for having done so. Rhode Island Aging and Disability Resource Centers, which are funded by the Administration for Community Living, help connect low- and moderate-income families to the respite programs.

AARP encourages states, localities, and voluntary organizations to learn from these promising practices by including robust respite programs in their existing HCBS systems. Respite is an important service that many family caregivers are likely to need and benefit from.

## Appendix A: Findings from literature review on respite services and their impact

### General respite results

Research shows that family caregivers benefit from respite.<sup>35</sup> Three systematic reviews of the evidence, which were published from 2007 through 2012, found that respite can reduce caregiver depression, distress, and anger.<sup>36</sup> One of these reviews found that respite for caregivers of frail older adults may improve the caregivers' mental or physical health.<sup>37</sup> This review found that caregivers were very satisfied with respite. One "rapid" systematic review of the literature found little evidence that respite helps caregivers.<sup>38</sup> The rapid review analyzed systematic reviews of care recipients of any age, whereas the first three systematic reviews focused on studies where care recipients were older adults.

In 2018, a survey of a representative sample of users of Older Americans Act program participants showed that caregivers who had in-home respite or respite in adult day service centers had better self-rated health compared to those who did not.<sup>39</sup> The health benefit of respite in adult day services centers was higher for caregivers ages 75 and over than for those ages 65 to 74.

### Dementia and respite

A separate body of literature exists on respite for family caregivers of people with dementia. The results show benefits. Two systematic reviews of the research found that respite can improve caregiver distress and depression.<sup>40</sup> Another review found equivocal evidence that respite helps caregivers of people with dementia.<sup>41</sup> This last review had a broad focus on a range of caregiver supports and types of care recipients.

<sup>35</sup> ARCH has an Annotated Bibliography of Respite and Crisis Care Studies. Additional studies are available at <https://archrespite.org/research/annotated-bibliography-of-respite-and-crisis-care-services/>.

<sup>36</sup> Maja Lopez-Hartmann, Johan Wens, Veronique Verhoeven, and Roy Remmen, "The Effect of Caregiver Support Interventions for Informal Caregivers of Community-Dwelling Frail Elderly: A Systematic Review," *International Journal of Integrated Care* 12 (2012); Chris Shaw, Rachel McNamara, K. Abrams, Rebecca Louise Cannings-John, Kerenza Hood, M. Longo, S. Myles, Marcella Sinead O'Mahony, Brenda Roe, and K. Williams, "Systematic Review of Respite Care in the Frail Elderly," *Health Technology Assessment* 13, no. 20 (2009): 1–246; A. H. Mason, H. Weatherly, K. Spilsbury, H. Arksey, S. Golder, J. Adamson, M. Drummond, and C. Glendinning, "A Systematic Review of the Effectiveness and Cost-Effectiveness of Different Models of Community-Based Respite Care for Frail Older People and Their Carers," *Health Technology Assessment-Southampton* 11, no. 15 (2007).

<sup>37</sup> Mason et al., "A Systematic Review."

<sup>38</sup> Gemma F. Spiers, Jennifer Liddle, Tafadzwa Patience Kunonga, Ishbel Orla Whitehead, Fiona Beyer, Daniel Stow, Claire Welsh, Sheena E. Ramsay, Dawn Craig, and Barbara Hanratty, "What Are the Consequences of Caring for Older People and What Interventions Are Effective for Supporting Unpaid Carers? A Rapid Review of Systematic Reviews." *British Medical Journal Open* 11, no. 9 (2021).

<sup>39</sup> Zhirui Chen, Ling Xu, and Christine Highfill, "Respite Services Utilization and Self-Rated Health of Older Family Caregivers in the United States: Differences between Young-Old and Old-Old Caregivers," *Journal of Social Service Research* 48, no. 1 (2022): 63–72.

<sup>40</sup> Sheung-Tak Cheng and Fan Zhang, "A Comprehensive Meta-Review of Systematic Reviews and Meta-Analyses on Nonpharmacological Interventions for Informal Dementia Caregivers." *BMC Geriatrics* 20, no. 1 (2020): 1–24; Erik Walter and Martin Pinquart, "How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis," *The Gerontologist* 60, no. 8 (2020): e609–19.

<sup>41</sup> Jane Dalton, Sian Thomas, Melissa Harden, Alison Eastwood, and Gillian Parker, "Updated Meta-Review of Evidence on Support for Carers," *Journal of Health Services Research & Policy* 23, no. 3 (2018): 196–207.

### Effectiveness of adult day services

Adult day services can provide either social services only (social model) or health and social services (health model). The evidence from six systematic reviews of adult day services shows the consistently positive impact of these models on caregiver distress, depression, and worry<sup>42</sup> for family caregivers of people with and without dementia. A review of 72 studies of various types found that caregivers are generally satisfied with adult day services.<sup>43</sup> Note that the reviews did not distinguish between social and medical models of adult day center services. Two of the reviews specifically excluded centers providing palliative and end-of-life services.

Two more recent individual studies of note show the following:

- Adult day services lower emotional and biological stress for caregivers of people with dementia.<sup>44</sup> This type of respite can also help educate and support caregivers.
- The caregivers of Black/African American adults with moderate dementia who used adult day services had fewer depression symptoms than those whose care recipients didn't use these services.<sup>45</sup> This was a cross-sectional study.<sup>46</sup>

The peer-reviewed literature on the effectiveness of respite services has some shortcomings, such as these:

- Definitions of respite vary, as do the family caregiver outcomes that researchers measure. In some cases, the definitions are vague. For example, the adult day services model is rarely specified in the literature this Spotlight cites.
- While there is much literature on caregiver interventions, often the studies don't single out respite.
- Ethical problems exist related to randomized controlled trials. For example, this kind of trial could force the family caregivers in the control group to forgo effective assistance for long periods to test the impact of respite. Zarit and colleagues assert that randomized controlled trials on respite have serious practical problems.<sup>47</sup> They recommend consideration of quasi-experimental and other research designs.

<sup>42</sup> Catherine Lunt, Christopher Dowrick, and Mari Lloyd-Williams, "What Is the Impact of Day Care on Older People with Long-Term Conditions: A Systematic Review," *Health & Social Care in the Community* 29, no. 5 (2021): 1201–21; Katharine Orellana, Jill Manthorpe, and Anthea Tinker, "Day Centres for Older People: A Systematically Conducted Scoping Review of Literature about Their Benefits, Purposes and How They Are Perceived," *Ageing & Society* 40, no. 1 (2020): 73–104; Virgínia Lúcia Reis Maffioletti, Maria Alice Tourinho Baptista, Raquel Luiza Santos, Valeska Marinho Rodrigues, and Marcia Cristina Nascimento Dourado, "Effectiveness of Day Care in Supporting Family Caregivers of People with Dementia: A Systematic Review," *Dementia & Neuropsychologia* 13 (2019): 268–83; Noelle L. Fields, Keith A. Anderson, and Holly Dabelko-Schoeny, "The Effectiveness of Adult Day Services for Older Adults: A Review of the Literature from 2000 to 2011," *Journal of Applied Gerontology* 33, no. 2 (2014): 130–63; Sophie Vandepitte, Nele Van Den Noortgate, Koen Putman, Sofie Verhaeghe, Caroline Verdonck, and Lieven Annemans, "Effectiveness of Respite Care in Supporting Informal Caregivers of Persons with Dementia: A Systematic Review," *International Journal of Geriatric Psychiatry* 31, no. 12 (2016): 1277–88; Moriah E. Ellen, Peter Demayo, Ariella Lange, and Michael G. Wilson, "Adult Day Center Programs and Their Associated Outcomes on Clients, Caregivers, and the Health System: A Scoping Review," *The Gerontologist* 57, no. 6 (2017): e85–e94.

<sup>43</sup> Ellen et al., "Adult Day Center Programs."

<sup>44</sup> Laura Cousino Klein, Kyungmin Kim, David M. Almeida, Elia E. Femia, Michael J. Rovine, and Steven H. Zarit, "Anticipating an Easier Day: Effects Of Adult Day Services on Daily Cortisol and Stress," *The Gerontologist* 56, no. 2 (2016): 303–12; Steven H. Zarit, "Past Is Prologue: How to Advance Caregiver Interventions," *Aging & Mental Health* 22, no. 6 (2018): 717–22.

<sup>45</sup> Lauren J. Parker and Laura N. Gitlin, "Does Adult Day Service Use Improve Well-Being of Black Caregivers of People Living with Dementia?," *Innovation in Aging* 5, no. 4 (2021).

<sup>46</sup> Cross-sectional studies analyze data from a population at a single time.

<sup>47</sup> Steven H. Zarit, Lauren R. Bangerter, Yin Liu, and Michael J. Rovine, "Exploring the Benefits of Respite Services to Family Caregivers: Methodological Issues and Current Findings," *Aging & Mental Health* 21, no. 3 (2017): 224–31.

Fortunately, the ARCH National Respite Network and Resource Center convened an expert panel to develop a research agenda related to respite services. The panel decided on six primary areas for the research recommendations:

1. Address foundational methodological concerns.
2. Research individual, family, and societal outcomes.
3. Conduct appropriate cost-benefit and cost-effectiveness research.
4. Research systems change that improves respite access.
5. Research improving competence of respite providers.
6. Conduct translational research that informs respite policy and practice.
7. Details on the recommendations can be found in ARCH's report.<sup>48</sup>

### Appendix B: Findings from literature review on factors affecting use of respite

Most of the research on factors affecting use of respite services focuses on caregivers of people with dementia. This section's discussion comes from three systematic reviews of the literature related to the impact of respite on family caregivers of people with dementia.<sup>49</sup> The review findings tend to overlap, so they are discussed together. The following factors, although specific to family caregivers of people with dementia, likely are similar to those that other family caregivers face.

**A person's background and values** affect family caregiver acceptance of respite, so programs need to be flexible to meet the caregiver's reality.

- Some populations tend to feel guilt about using respite. For example, white and Black/African Americans appear to feel more guilt about using respite than Hispanic/Latino Americans do. Program outreach to each of these groups needs to be different.
- The relationship between the family caregiver and the person with disabilities affects acceptance of respite. Those more likely to use respite are wives, older adult caregivers, and children of a person with dementia. Some spouses are less likely to use respite because of their marital bond or sense of duty. Men are also less likely than women to use respite. Outreach methods need to be tailored to these groups.
- Caregivers' feelings can affect use of respite. Some family caregivers may feel that they don't have a right to respite or don't need it. Caregivers may feel that, if they accept respite, they have failed their care recipients or benefited only themselves. Perhaps programs need to communicate to caregivers the importance of taking care of themselves. Caregivers need to understand that their ability to help their care recipients depends, in part, on their own health.

<sup>48</sup> Raymond S. Kirk, Susan Summers, ARCH National Respite Network and Resource Center, "Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders," 2021.

<sup>49</sup> Marie-Conception Leocadie, Marie-Hélène Roy, and Monique Rothan-Tondeur, "Barriers and Enablers in the Use of Respite Interventions by Caregivers of People with Dementia: An Integrative Review," *Archives of Public Health* 76 (2018): 1–11; Emma O. Shea, Suzanne Timmons, Eamon O. Shea, Siobhan Fox, and Kate Irving, "Key Stakeholders' Experiences of Respite Services for People with Dementia and Their Perspectives on Respite Service Development: A Qualitative Systematic Review," *BMC Geriatrics* 17, no. 1 (2017): 1–14; Christine Neville, Elizabeth Beattie, Elaine Fielding, and Margaret MacAndrew, "Literature Review: Use of Respite by Carers of People with Dementia," *Health & Social Care in the Community* 23, no. 1 (2015): 51–63.

**Caregivers with higher levels of responsibility or for longer periods of time** are more likely to use respite. This is true of family caregivers who have been caring for a care recipient for five years or longer or have been caring for someone who has problematic behavioral symptoms of dementia or a high-level disability. Caregivers with busy schedules or high feelings of distress are also more likely to use respite. Targeting respite outreach to these groups may be particularly effective.

**Communication** can affect respite use. Caregivers who don't know about the availability of respite or how to use it face barriers. However, too much information can be confusing. Good communication between the family caregiver, staff, and the person with dementia is key to high-quality care in the view of all three parties.

**Respite design**, particularly flexibility, can affect use of the service. Tailoring services to the needs of family caregivers and the person with dementia is the key to good design.

- Family caregivers are more likely to use respite services that are easy to arrange, especially during emergencies; of good quality; and accessible.
- Caregivers prioritize the following types of respite services: help with the care recipient's daily activities and monitoring and ensuring that the person with dementia engages in activities that are meaningful to them. Caregivers also prefer in-home services with longer periods of respite. In-home services address problems related to lack of transportation and inconvenient places and times for respite.
- Caregivers want more control over respite as well as the ability to choose staff and to have a consistent set of staff coming into the home.

The lessons from this research are that tailored communications, flexible and accessible services, and trained staff delivering high-quality care are important. A respite program that takes this into account will be better able to meet the needs of family caregivers and their care recipients.

### Appendix C: Detailed recommendations from prior respite reports

Many policymakers recognize the importance of family caregivers in taking care of people of all ages with disabilities. And experts have produced six recent major reports with policy recommendations designed to assist family caregivers. Among the recommendations are many related to respite services.

This section summarizes and expands on recommendations from the six reports<sup>50</sup> that several groups prepared as well as experts<sup>51</sup> we consulted. The reports came from the following entities:

- Federal RAISE Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren

<sup>50</sup> Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & Advisory Council to Support Grandparents Raising Grandchildren, "First Principles: Cross-Cutting Considerations for Family Caregiver Support," 2022; RAISE Act Family Caregiving Advisory Council & Advisory Council to Support Grandparents Raising Grandchildren, "2022 National Strategy to Support Family Caregivers," 2022; RAISE Act Family Caregiving Advisory Council & Advisory Council to Support Grandparents Raising Grandchildren, "National Strategy to Support Family Caregivers: Actions for States, Communities, and Others," 2022; Wendy Fox-Grage, "Inventory of Key Family Caregiver Recommendations," National Academy for State Health Policy, 2020; Richard Schulz and Jill Eden (eds.), *Committee on Family Caregiving for Older Adults: Families Caring for an Aging America*, National Academies Press, 2016; Miriam S. Rose, Linda S. Noelker, and Jill Kagan, "Improving Policies for Caregiver Respite Services," *The Gerontologist* 55, no. 2 (2015): 302–8.

<sup>51</sup> Experts include Lynn Feinberg, retired family caregiver expert; Wendy Fox-Grage from the National Academy for State Health Policy; Jill Kagan from the ARCH National Respite Network & Resource Center; Kathy Kelly from the Family Caregiver Alliance; Greg Link from the Administration for Community Living.

- The National Academies Committee on Family Caregiving for Older Adults, Families Caring for an Aging America
- National Academy for State Health Policy’s inventory of caregiving recommendations
- The ARCH National Respite Network’s recommendations on respite

The first three sources were national efforts to address the totality of caregiver well-being; respite appeared in their larger sets of recommendations. The ARCH National Respite Network is the key organization in the development of policy and programs specific to respite.

Since these sources’ recommendations overlap substantially, the following recommendations are distilled and consolidated from these reports and consultations with caregiver and respite experts.

Policy recommendations are that respite programs need to do the following:

- **Use a broad and standard definition of respite.** Distilled to its essence, the recommendation is to define respite as *any activity that provides the caregiver with a meaningful break from their responsibilities*. A core principle for respite is that the available services are flexible and meaningful to the caregiver. This is important because each caregiving situation is unique. Here are examples of flexible respite:
  - A short break from any caregiving task, like help with medical tasks, daily activities, household tasks, or supervision for someone with cognitive impairment
  - Companionship for the person with disabilities so the family caregiver can do other things
  - Doing housekeeping tasks that the caregiver would normally do
  - Creating space in the caregiver’s day for a nap or a walk
- **Assess and regularly reassess needs.** This is important because family caregivers and their care recipients’ situations change over time. For example, people with progressive conditions like dementia or Parkinson’s disease have needs for assistance that get more intense over time as the condition worsens. If a family caregiver or one of their other care recipients gets sick, the family caregiver may have less capacity to help the person with disabilities. Generally, recommendations are to assess need when entering a program and again when the caregiving situation changes.
- **Focus on the needs and choices of the family caregivers.** Almost all LTSS programs focus on the needs of the person with disabilities, who is generally the participant in the LTSS program. Often, during the assessment and care management process, the program assumes some level of assistance from family caregivers. Little if any attention may be paid to the needs and abilities of the family caregivers. So, a focus on the needs of family caregivers and the choices they make about the type of respite they receive is important. This type of care is family centered.
- **Address any trauma that caregivers face.** Traumas can include lack of control over the family caregiving situation, high demands on the caregivers’ time, and watching a care recipient’s physical or mental health deteriorate over time. Surprise medical events, such as strokes or heart attacks or living with the threat of them, can be traumatic. Addressing these challenges and their impact on the family caregiver is important during assessment and care planning.
- **Address cultural expectations, differences within communities, effects of discrimination, and nontraditional families.** An example of these situations happens when people who are lesbian, gay, or transgender are afraid to let others know because of the widespread discrimination they face. Likewise, people of color generally have experienced decades of discrimination, and programs may lack cultural sensitivity to their needs and expectations.

- **Ensure that family caregivers know about the availability of respite in their communities and have easy access to the service.** As the respite research indicates, family caregivers often don't know about available respite, find using it to be confusing, and have difficulty getting services that work for them and their care recipients. So, attention to clear and simple communications and instructions about how to access respite is important. In addition, people need information and resources in their primary language.
- **Train and pay the professional workforce well to ensure high-quality services.** Staff turnover among LTSS workers is quite high. Researchers attribute this to low pay, few benefits, poor supervision, and little training, in addition to the difficult and delicate work of caring for people with disabilities. Addressing these issues would help ensure access to reliable and trusted respite services for family caregivers.
- **Ensure that respite is flexible.** Here, “flexibility” means meeting the family caregivers’ needs and honoring their choices about respite services. Here are considerations that can help ensure flexibility:
  - Services need to be available in the home and outside of it. Facility-based respite is one approach for families who want to go on vacations or do other family activities.
  - Some family caregivers want to manage their own services, so availability of self-directed services is important.
  - Adult day services have become less available during the COVID-19 pandemic. However, this form of respite has some of the best results for family caregivers.
- **Ensure that respite is affordable.** If family caregivers and their care recipients can't afford respite and don't qualify for available governmental programs like Medicaid, they likely won't get the respite they need or want. Volunteer respite is one option that can help with affordability of services, especially in rural and other underserved areas. For example, faith-based drop-in programs can be more affordable than traditional adult day services.

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