



Innovations and Scaling in Respite Services Delivery and Outreach



May 22, 2024

About the AARP Public Policy Institute

- The AARP Public Policy Institute (PPI) is the focal point of public policy research, analysis and development at AARP.
- “Think and do tank”- identify and help advance solutions to critical policy problems
- Within PPI, our LTSS Choices initiative seeks to spark and help spread innovation in LTSS and to support family caregivers.
- Key websites:
 - www.AARP.org/PPI
 - LTSSChoices.AARP.org (do not include www prefix)

AARP PPI's Respite Work

- Spotlight report in January 2024
- Indicator in the 2023 LTSS State Scorecard
- Family caregiving research and data
- More to come...



LTSS CHOICES

Respite Services: A Critical Support for Family Caregivers

Susan Reinhard, Jane Tilly, Brendan Flinn

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 or 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 Act¹ 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

¹The 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.

1 | AARP Public Policy Institute © 2023 ALL RIGHTS RESERVED | ltsschoices.aarp.org

AARP PPI's approach to respite

- Consider respite holistically- across payers, provider types
- Focus on services that provide breaks to family caregivers
- Highlight both innovative models and gaps in current policy and financing frameworks
- Spotlight the importance of respite to family caregivers
 - Just 1 in 7 family caregivers receive respite in some form, yet more than one-third want this support.

What do we know about family caregivers?

- As of 2020:
 - 48 million family caregivers (both relatives and nonrelatives) who provide on average 18 hours of care per week.
 - Most support an adult 50+
 - More than 6 in 10 are women, more than 6 in 10 balance work and caregiving
 - Family caregivers are more diverse by race/ethnicity compared to the general population.

Economic Value of Family Caregiving

- In 2021, family caregivers provided \$600 billion worth of unpaid care to people they support.
 - AARP provides estimates for each state (NY: \$39 billion)
- Exceeds total US (including out-of-pocket) spending on LTSS including post-acute care.
- Reinforces the need for robust supports including respite care.
- Key webpage: www.aarp.org/valuing

Factors Affecting the Use of Respite

We reviewed the literature and systematic literature reviews on respite. Four key themes emerged:

- A person's background and values affect family caregiver acceptance of respite.
- Caregivers with higher levels of responsibility or for longer periods of time are more likely to use respite.
- Communication can affect respite use. Targeted outreach needed.
- Respite design, particularly flexibility, can affect use of the service.

Barriers to Respite Access

We also sought to identify barriers to respite access. Importantly, many of these are **not** within the control of individual providers-underscoring the importance of policy support for respite care.

- 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,
- Lack of trained respite providers



Public Financing for Respite

Public financing for respite in the United States

Various federal and state programs help pay for respite, many of which come with restrictions on how much and who can qualify.

- Medicare
- Medicaid
- Veterans' programs
- Other federal programs that support respite and family caregivers
- State-funded programs

Respite in Medicare (1/3)

- 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.
- 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 home health benefit may also be experienced as respite, although that is not its primary objective.

Respite in Medicare (2/3)

- Federal legislation and regulation expanded access to what are known as supplemental benefits to Medicare Advantage.
- Some of these benefit categories provide respite or similar services.
- Plans have immense discretion, which may lead to narrow or functionally inaccessible ‘benefits’
- Lack of transparency regarding utilization, uptake, and more.

Respite in Medicare (3/3)

- We do know that plans are increasing *where* HCBS-specific supplemental benefits are offered.
 - For the in-home supports and caregiver support benefit categories, the number of plans increased by 4x 2020-2024.
- Disparate access for beneficiaries with traditional Medicare- they do not have access to any of these benefits.

Respite in Medicaid (1/3)

- Medicaid defines respite as intermittent or regularly scheduled temporary medical care and/or supervision of the participant.
- Respite can be offered through multiple types of Medicaid HCBS programs and across settings.
- Other services may provide the ‘experience’ of respite even if outside the specific service type.

Respite in Medicaid (2/3)

- States have extensive flexibility in Medicaid waivers so long as they operate within basic federal rules.
 - Who can qualify, who can provide services, reimbursements, caps and limitations.
- In general, individuals must have almost no income or assets to qualify.
- Respite (.5%) and adult day services (1%) comprise a small portion of state budget estimates for 1915c waivers.

Respite in Medicaid (3/3)

- Despite limitations, states can choose to offer robust options within the Medicaid program. Additional research spotlights innovations for respite in waivers.
- The American Rescue Plan Act (2021 COVID relief) provided new funding to Medicaid HCBS, of which some states opted to fund respite.
- More data needed to better understand utilization, payments, and impact on consumers and families.

Respite in VA 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.
 - Cash benefits do not provide respite directly but could provide funding families need to pay for care.

Respite across federal programs (1/2)

- Outside the primary health/LTSS payers, several critical federal programs support respite.
 - Lifespan Respite Care Program
 - National Family Caregiver Support Program
 - AmeriCorps Senior Companion Program
- Funding for these programs do not meet demand or needs of older adults and family caregivers.

Respite across federal programs (2/2)

- Research shows these federal programs **work** and help consumers and families.
 - A 2018 evaluation of NFCSP found that respite was a popular and frequently requested service, and many of those who don't receive it either didn't know about it or were not eligible.
 - Family caregivers in the Senior Companion Program report less depression, stress, and time constraints as well as better social connections and physical and mental health.

State funded respite programs

- States can and do choose to fund respite without federal dollars.
- Often offered in conjunction with other HCBS to non-Medicaid eligible populations.
- Select examples:
 - Arizona's Non-Medical Home and Community Based Services Program helps older adults remain at home with a range of services including adult day and respite. Priority goes to older adults based on their functional & financial needs.
 - 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.
 - South Carolina's respite voucher program is for people with Alzheimer's disease.



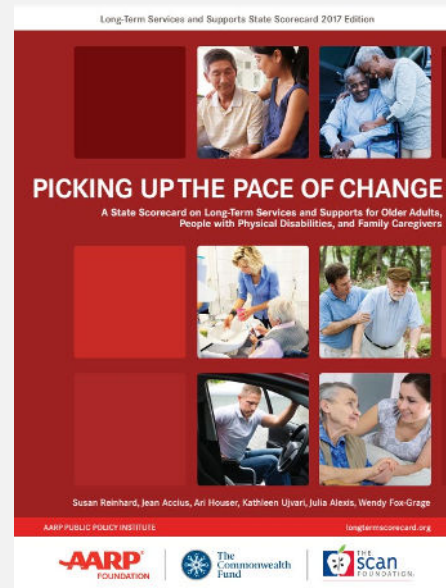
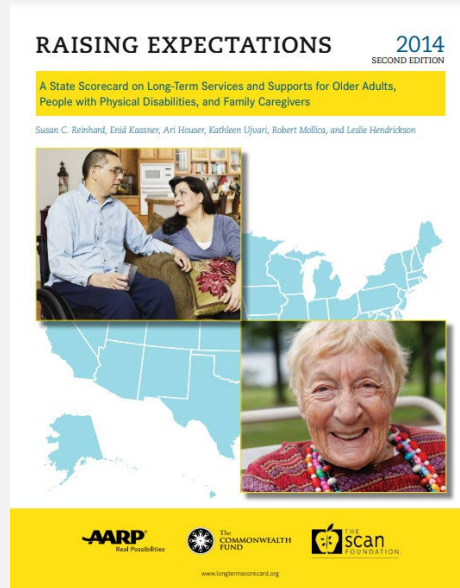
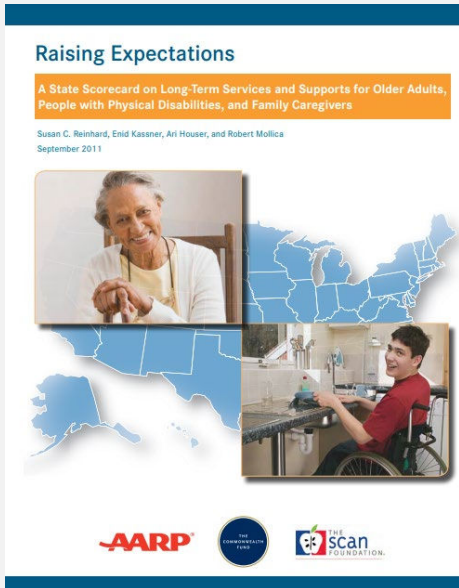
Respite in the LTSS State Scorecard

Respite in the LTSS State Scorecard

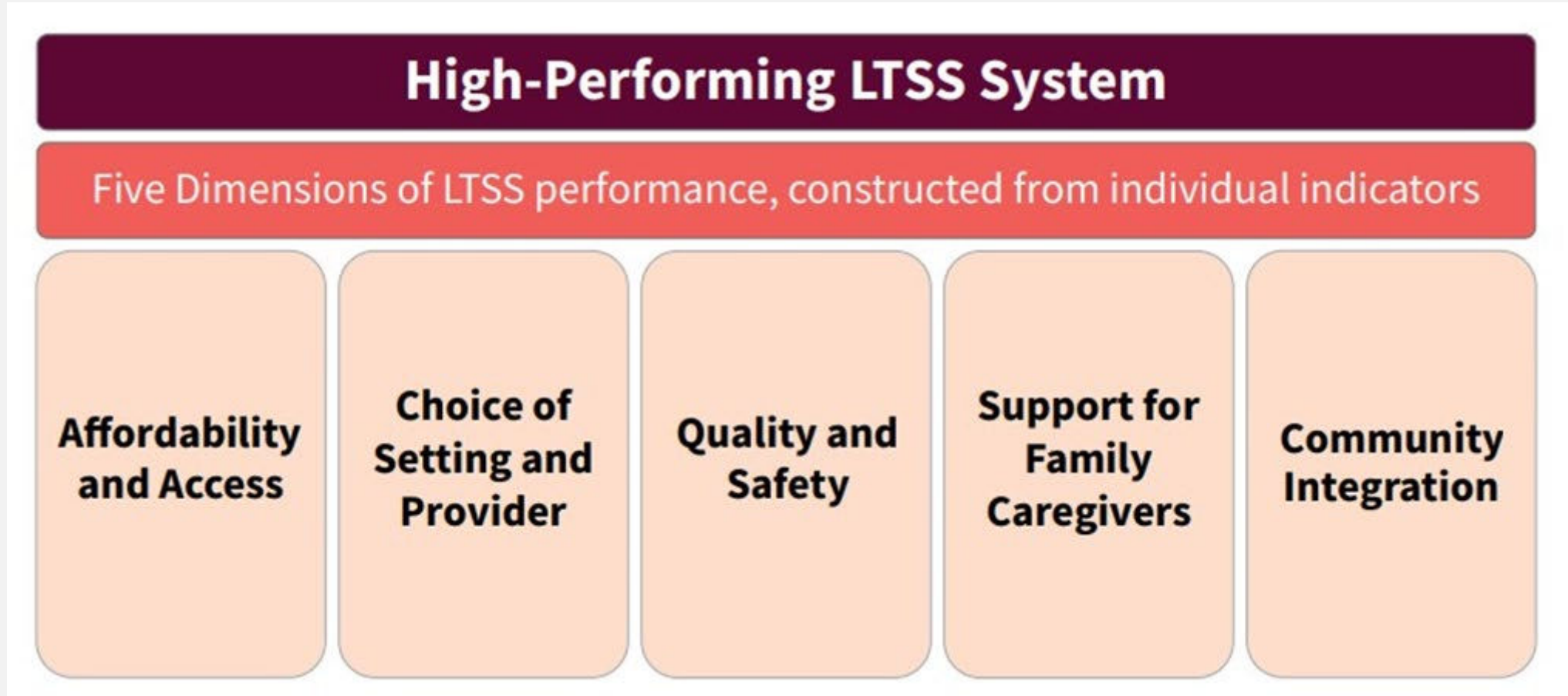
- The 2023 LTSS State Scorecard for the first time includes an indicator specific to respite services, measuring how state Medicaid HCBS waiver programs provide access to respite.
- We found that most states have a respite benefit written into their HCBS waivers for older adults and/or people with physical disabilities.

Our Fifth Scorecard!

Published every 3 years since 2011!



LTSS State *Scorecard* Framework



Respite in the LTSS State Scorecard

- Very limited, reliable data exists on Medicaid HCBS program services, so we consider this indicator a first step designed to draw more attention to respite in the report.
- Using an analysis from NASHP, we granted full credit to states that did not have a limit on respite written into the waiver document, and partial credit to those who included respite with any arbitrary limit written in.
- States that relied entirely on the person's person-centered plan to determine respite access received full credit.

Additional key *Scorecard* findings

- For the first time, more than half of Medicaid LTSS dollars for older adults and people with physical disabilities went to HCBS- including respite.
- Availability of services remains a concern, especially for settings like home-based care and adult day services.
- Cost for services of all sorts increased across states and are largely unaffordable to most families.
- States with more robust supports for family caregivers (including respite) were the states that performed best overall for system performance.



Diffusion of Innovation Across LTSS and in Respite

Diffusion of Innovation Across LTSS

- Through five models of delivery that have shown scale, AARP PPI studied how to best diffuse innovation specifically in LTSS.
- Employed the Rogers Model:
 - Relative advantage
 - Compatibility
 - Complexity
 - Trialability
 - Observability

Diffusion of Innovation Across LTSS

- Innovators trying to solve problems with their state and local LTSS systems
- Innovations that are compatible with the ethics and needs of the innovators
- Local and state level experimentation that demonstrates the cost-effectiveness of the innovations
- All stakeholders considering equity as a key component across the scaling process.

Diffusion of Innovation Across LTSS

- Foundations and government policy makers working together to test and refine the innovations and providing technical assistance to reduce complexity, costs, and risks for potential adopters
- Successful innovations, in terms of diffusion, that have backers who disseminate information about them
- Policy makers who alter policy, increase funding, and provide technical assistance to help states and localities expand the innovations

Ways to Improve Respite Access

Several reports have studied ways to improve respite across the board. Many of these are more macro oriented and require buy-in from agencies and policymakers, but some can be adopted individually by providers.

- 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
- ensuring that respite is flexible and affordable.

Innovations in Respite Services (1/2)

- 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.
- Promising models and practices may help inform development of new programs or expansions of those existing.
- Potential for scale is rich across the board.

Innovations in Respite Services (2/2)

- Key state examples of innovation in respite
 - Alabama
 - California
 - New York
 - Rhode Island

Opportunities for the Future

- Continue to invest in HCBS infrastructure
- Build and strengthen coalitions to drive change
- Boost supports for family caregivers and paid workers
- More robust HCBS data, including demographics
- Build stronger and more equitable communities.

Thank you!

- www.aarp.org/ppi
- LTSSChoices.AARP.org
- [Email: bflinn@aarp.org](mailto:bflinn@aarp.org)