

THE ROLE OF RESPITE IN THE
National Strategy to Support Family Caregivers

An ARCH Policy to Practice Brief

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ARCH National Respite Network and Resource Center



ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network includes the National Respite Locator that helps caregivers and professionals locate respite services in their community; the National Respite Coalition, which is the policy division of ARCH; and the Lifespan Respite Technical Assistance and Resource Center, funded by the Administration for Community Living in the U.S. Department of Health and Human Services.

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THE NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

The [2022 National Strategy to Support Family Caregivers](#) was created to support family caregivers of all ages, from youth to grandparents, regardless of where they live or what caregiving looks like for them and their loved ones. The strategy was developed jointly by the advisory councils created by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act, with extensive input from the public, including family caregivers and the people they support. The Strategy will be updated in response to public comments and will evolve with the caregiving landscape.

The Strategy includes nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy, and more than 150 actions that states, communities and others in the public and private sectors can take to support the nation's family caregivers.

For more information, visit the Administration for Community Living: [National Strategy to Support Family Caregivers](#)

THE LIFESPAN RESPITE CARE PROGRAM

The [Lifespan Respite Care Program](#), enacted under Title XXIX of the Public Health Service Act (42 U.S.C. 201) in 2006 and reauthorized January 2021, was created to support the more than **50 million American caregivers** who provide continuous care to their spouses, children, grandchildren and other family members with a disability or health condition.¹

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to caregivers.

The [Lifespan Respite Care Program](#) does not supplant other funding sources. Rather, *it capitalizes and improves upon existing assets*. Through local knowledge of the unique needs and resources in their states, regions and communities, state Lifespan Respite Program grantees work with key partners to address the universal need of family caregivers to receive temporary relief from providing continuous care to loved ones over extended periods of time.

Through competitive grants, the Lifespan Respite Care Program supports individual state grantees to achieve [five objectives](#).²

1. [Expand and enhance respite services in the states;](#)
2. [Improve coordination and dissemination of respite services;](#)
3. [Streamline access to programs;](#)
4. [Fill gaps in service where necessary; and](#)
5. [Improve the overall quality of respite services where available.](#)

The [Lifespan Respite Care Program](#) supports states' efforts to create respite *systems*. These systems work to coordinate across agencies so that families have access to respite regardless of age, disability, or chronic condition.

Respite *systems* may sound abstract and distant from the day-to-day reality of caregivers' lives. In practice, however, state [Lifespan Respite Program](#) grantees, in partnership and coordination with State Respite Coalitions and Aging and Disability Resource Centers/No Wrong Door systems, orchestrate activities that translate to essential services for caregivers and their families. Coordinated respite systems strive to provide family caregivers with the services below:

- ◆ online information and access to respite services;
- ◆ individualized support in understanding and navigating respite and related support services;
- ◆ vouchers that reduce or eliminate respite costs for family caregivers;

- ◆ respite care in family settings, and in local volunteer and faith-organizations, colleges, and community programs; and
- ◆ training to strengthen the capacity of individuals, organizations, and communities to provide competent, reliable care to families.

The daily activities state respite programs and coalitions accomplish within state respite systems are invaluable in understanding and implementing the *National Strategy to Support Family Caregivers*.

THE IMPORTANCE OF RESPITE IN THE NATIONAL STRATEGY

The 2022 National Strategy to Support Family Caregivers includes an abundance of important and relevant information and guidance to support caregivers. Given the breadth and complexity of the Strategy, the purpose of this brief is to establish the unique role that Lifespan Respite grantees and their partners can play in streamlining implementation of the Strategy's recommended respite actions. The intent of this paper is also to make it easier for agencies, providers, and others to identify specific actions they can take to implement the Strategy's recommended respite actions in their day-to-day practice.

To clarify the important role that respite could, and should, play in realizing the promise of the National Strategy, we show explicit examples and unique opportunities to implement the identified respite actions through existing Lifespan Respite programs, services, and systems. These examples and opportunities reside in four areas: **Planning and Decision-Making; Information and Access; Person- and Family-Centered Services; and Workforce Development.**

1. Planning and Decision-Making

In the introduction to this Policy to Practice Brief, we note that the [2022 National Strategy to Support Family Caregivers](#) is a living document that will be updated in response to public comments and *will evolve with the caregiving landscape*. This necessitates hearing from people closest to the implementation of these recommendations, especially those most effected by them — family caregivers and service providers.

State Lifespan Respite grantees and their State Respite Coalition partners can and should play a role in involving all stakeholders — family caregivers, state, local and community organizations and agencies, and community ambassadors, for example. Involved stakeholders through State Respite Coalitions have a history of and expertise in assessing community needs and resources, planning and participating in deliberative and decision-making bodies, and aligning services and funding resources. State Lifespan Respite grantees and their partners have discovered that even within those agencies that permit and make funding available for respite services, at times those in leadership positions are not aware that they are permitted to support respite services. Some in leadership positions are unaware exactly what respite is and why caregivers identify respite services as their greatest need or priorities.

Educating and involving stakeholders according to their level of awareness and understanding are prerequisite to coordinated and collaborative planning and decision making that streamlines access to respite for family caregivers. Respite grantees and coalitions have a long history of successful collaborations with businesses, higher education, health care systems, child welfare, tribal nations, among others, and especially important, with family caregivers. For those states without a functioning Lifespan Respite grant or State Respite Coalition, using the lifespan respite systems building model and adopting an inclusive, systematic approach could be foundational for implementing respite actions recommended in the National Strategy.

2. Information and Access

The [National Strategy](#) describes a number of conditions that compromise family caregivers' access to services — lack of flexibility or understanding of caregiving demands in the workplace; lack of understanding of available services and supports and how to find and afford them; lack of available persons and programs that are culturally or linguistically competent to serve all families; and lack of available human supports to offer guidance and follow-up as family caregivers navigate multiple systems or experience changes in their caregiving circumstances.

Respite systems and programs across the nation have grappled with all of these challenges and worked to address them. Many state Lifespan Respite grantees and coalitions have created or participate in an internet navigator or No Wrong Door system that organizes caregiver information and makes it easily accessible. Some navigator systems employ persons who work one-to-one to help caregivers navigate complicated systems in real time. An important addition to the navigation practice and process might include “touchpoints” — the identification of times when caregivers and families are likely to first need accurate and sufficient information and support in choosing and using caregiver services, including respite. Touchpoints might include, for example: when “stepdown” from ICUs and NICUs occur; from hospital to home; times of developmental assessments at tertiary care centers; times of mental/behavioral and physical health/illness diagnosis; times of Alzheimer’s and memory illness diagnosis; times when caregivers and families are experiencing difficult life circumstances or emergencies; times when caregiving responsibilities are in flux or change permanently, as with grandparents, extended family, or foster family caregiving.

Ambassadors who are trusted members in cultural and ethnic communities that could benefit from, but do not have access to respite, can help identify important touchpoints. Ambassadors could also educate service providers and policy makers about ways to effectively reach and form relationships with communities to increase

information sharing and assure access to services and resources that are preferred by those communities. Some State Respite Coalitions and individual respite service providers and programs that have historically served and evaluated respite in diverse communities can share their expertise and insight on how they have successfully reached, partnered with, and served those communities.

Identifying touchpoints is also important for caregiver self-identification and knowledge of services and resources. It is essential to note that information and support cannot be offered in a one-time communication. Caregivers' needs occur in human time rather than institutional time. Emergencies occur. Prolonged caregiving may increase emotional and physical stress cumulatively. Lifespan Respite grantees and other respite programs in the National Respite Network have shown that during times of stress, and over time, walking with caregivers and families, listening and exchanging information, making sure there is a warm handoff to service providers and resources, checking in to see that things are working for caregivers and families, and course correcting are all essential. Respite research also indicates that supporting caregivers in planning for how they use their respite time can reduce caregiver stress and increase satisfaction with services. This is an example of a practice that could be incorporated in the navigation process from the outset.

For working caregivers, Lifespan Respite grantees and their partners have been educating employers about the needs of their employed caregivers through anonymous workplace surveys. They have also been partnering with other state agencies, such as Departments of Labor, to engage employers to disseminate information in the workplace about respite and caregiver supports through Employee Assistance Programs, lunch and learns, and printed materials.

3. Person- and Family-Centered Services

Person- and family-centered services are a key focus of the [National Strategy](#), and are included as a goal to ensure that services and supports are diverse, flexible, and match caregiver and care recipient needs as circumstances change over time.

Respite services are intentionally designed to be flexible and individualized. Even those caregiving families who receive regular long-term services and support may also desire and can benefit from respite. For example, an older adult family caregiver works full-time while her adult son attends a day services program. This is enormously helpful to her in continuing to work and earn money to support herself and her family. This caregiver may also like to share a meal at a restaurant with friends on occasion, or participate in a caregiver support group, or attend a worship service. Respite provides opportunities to caregivers to participate in activities meaningful to them, according to their individual circumstances, in ways that help them feel socially connected and supported, and that reduce stress and isolation. When providing person- and family-centered services, it is important to work collaboratively in planning, providing, and evaluating services.

It is also important to view the lives of family caregivers, care recipients, and family members in the broader contexts of relationships, community, and individual health and well-being. Respite services tend to be individually matched and tailored in ways that support caregivers and families in important contexts and in culturally informed ways. Respite programs, capitalizing on close relationships with caregivers and families formed over time, increasingly include individualized emergency planning and long-term planning services to caregivers and families. ARCH has observed that some community-based respite programs have influenced positive change by enhancing socialization opportunities for people with disabilities in faith communities, neighborhoods, and broader communities through messaging and their good example of inclusiveness.

4. Workforce Development

The National Strategy acknowledges and emphasizes the detrimental effects of longstanding shortages in the caregiving workforce. National and state attention to this worker crisis are providing new opportunities to expand and train the direct care workforce — a goal respite programs and systems have long endeavored to address.

Respite programs and services, like most long-term services and supports, struggle to recruit, train, support, and retain direct service providers. A number of volunteer respite programs provide important insights on how to accomplish these tasks (including matching volunteer providers and families) while improving *both* caregiver satisfaction *and* volunteer direct service provider satisfaction, and retaining volunteer direct service providers for extended periods of time. The relative flexibility and low cost of respite voucher programs, and volunteer and faith-based volunteer models of service delivery, when constructed in ways that benefit families through navigation and support, individualized services, and inclusion in communities that welcome and support caregivers and families, make respite essential to conversations about supporting all caregivers. The national lifespan respite network is also at the forefront of developing and evaluating respite provider recruitment strategies and training that will likely have important implications for how other programs and institutions serving caregivers and their families grow their workforce.

SUMMARY

Respite services — often created and designed by caregivers to meet observed needs in given communities and based on their intimate knowledge of what caregivers and families want and need — are offered because the service organization or individual provider *wants* to connect and help caregivers and families. Respite services tend not to be bureaucratic, officious, or top-down. Rather, they tend to be person- and family-centered, and rooted in community. Existing respite programs and services offer

instruction and wisdom in structuring and delivering services *with* caregivers and families.

An ongoing study by ARCH of Innovative and Exemplary respite programs and services, and recent Innovative and Exemplary Evaluation Project Initiative, demonstrates real innovation in service models and approaches, including novel and seamless (at least to families) ways of funding services, and a commitment to understanding what is working for caregivers and families based on sound measurement practices and formal evaluation. These programs and services offer fertile ground for learning and replication.

No matter what other services are available and offered to caregivers and their families, respite is a high priority according to caregivers. Ideally, in addition to other support services, respite should be universally and flexibly available in order to accommodate individual and family daily and emergency circumstances, and to the extent possible, be scheduled according to when and how caregivers and families choose to use respite.

Looking to Lifespan Respite Care Program grantees, their partners, and ARCH-recognized Innovative and Exemplary Respite services will lead the way to improved access and efficiency in service delivery, and to easily replicable respite services that are meaningful and trusted by caregivers and families who rely on them for support.

ENDNOTES

¹ National Alliance for Caregiving and AARP Public Policy Institute (2020). *Caregiving in the U.S. 2020*. Washington, DC: Authors. www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020

² U.S. Department of Health and Human Services. Administration for Community Living. *Lifespan Respite Care Program*. acl.gov/programs/support-caregivers/lifespan-respite-care-program