

Lifespan Respite 101: Who, What, Why, Where and How!

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ARCH
National Respite Network
AND RESOURCE CENTER

Asking for Help

**is a sign of
strength.**

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ARCH
National Respite Network
AND RESOURCE CENTER

- **Training and Technical Assistance Division** provides support to State Respite Coalitions, service providers and families through consultation, training, evaluation, and research.
- **National Respite Locator Service (NRLS)** helps family caregivers and professionals locate respite services in their communities.
- **National Respite Coalition** is the policy and advocacy division of ARCH.
- **Lifespan Respite Technical Assistance Center**, funded by the U.S. Administration for Community Living, supports State Lifespan Respite grantees and their partners in developing state respite systems serving caregivers of persons of all ages and conditions.

Presentation Overview

- Family Caregiving in the U.S.
- Respite Definition, Benefits, Access, Barriers
- Lifespan Respite Care Program
 - Federal Administration and Requirements
 - Partner Roles
 - Lifespan Respite Grantee Activities
- ARCH Resources & Initiatives



Snapshot of Caregiving in the U.S.

63 million family caregivers in the U.S., up from 43 million in 2015

15.5 million children with special health care needs

45% in high intensity caregiving situations

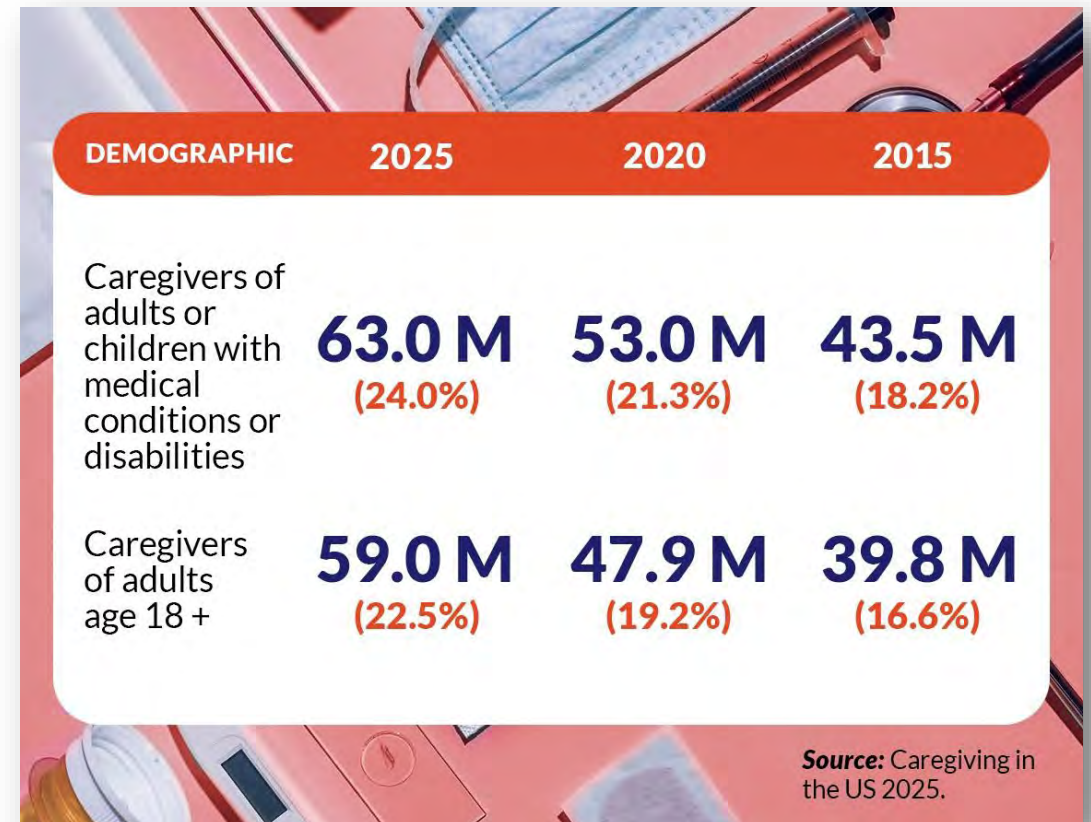
29% are sandwich generation caregivers

60% are working while caregiving

Sources:

Caregiving in the U.S. 2025, National Alliance for Caregiving and AARP, <https://www.caregivingintheus.org/>

Child and Adolescent Health Measurement Initiative. 2023-2024 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health, <https://www.childhealthdata.org/>





Respite Benefits and Barriers



Respite is...

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

*Lifespan Respite Care Act definition
PL 109-442*



Benefits of Respite

- Promotes community living
- Reduces caregiver stress, anxiety, depression
- Improves caregiver physical and emotional health
- Enhances relationships and reduces social isolation
- Care recipients benefit, too!

Source: Leocadie, MC., et al. (2018). Barriers and enablers in the use of respite interventions by caregivers of people with dementia: an integrative review. *Arch Public Health* **76**, 72.





Respite Underutilization: Too Little, Too Late

- Caregivers' highest demand is for respite services - nearly four in 10 family caregivers identify respite as their top service need.
- Overall, 87% of family caregivers are not receiving respite services.
- Of those who use respite, they often receive too little, too late.



Sources:

National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2025*

Yeunkyung Kim, et al. (2024). Trend in Respite Use by Race Among Caregivers for People Living With Dementia, *The Journals of Gerontology: Series A*, Vol 79, Issue Supplement_1

Respite Barriers

- Not aware of respite or benefits
- Reluctance to use respite
- Cost
- Concern about quality of care
 - Shortage of qualified, trained providers
 - Limited and inflexible respite options
- Access Issues
 - Navigating services in a fragmented system
 - Lack of information on how to find, choose, pay for and use respite



Bureaucratic Maze of Funding

- ❑ Medicaid Waivers
- ❑ Medicare (GUIDE, Advantage Plans, Hospice)
- ❑ Family Caregiver Support Program
- ❑ Veterans Caregiver Support Program
- ❑ Other Federal Programs
- ❑ State Funded Respite Programs
- ❑ Private Sector Options





Lifespan Respite Care Program



Lifespan Respite Care Program

Definition: Coordinated **SYSTEMS** of accessible, community-based respite services for family caregivers regardless of age or special need of the care recipient.

Read more on the acl.gov webpage: <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>

Lifespan Respite Care Program

Like a quilt, it weaves together important, but fragmented funding streams, disparate and duplicative programs, and eligibility silos to form a seamless system.



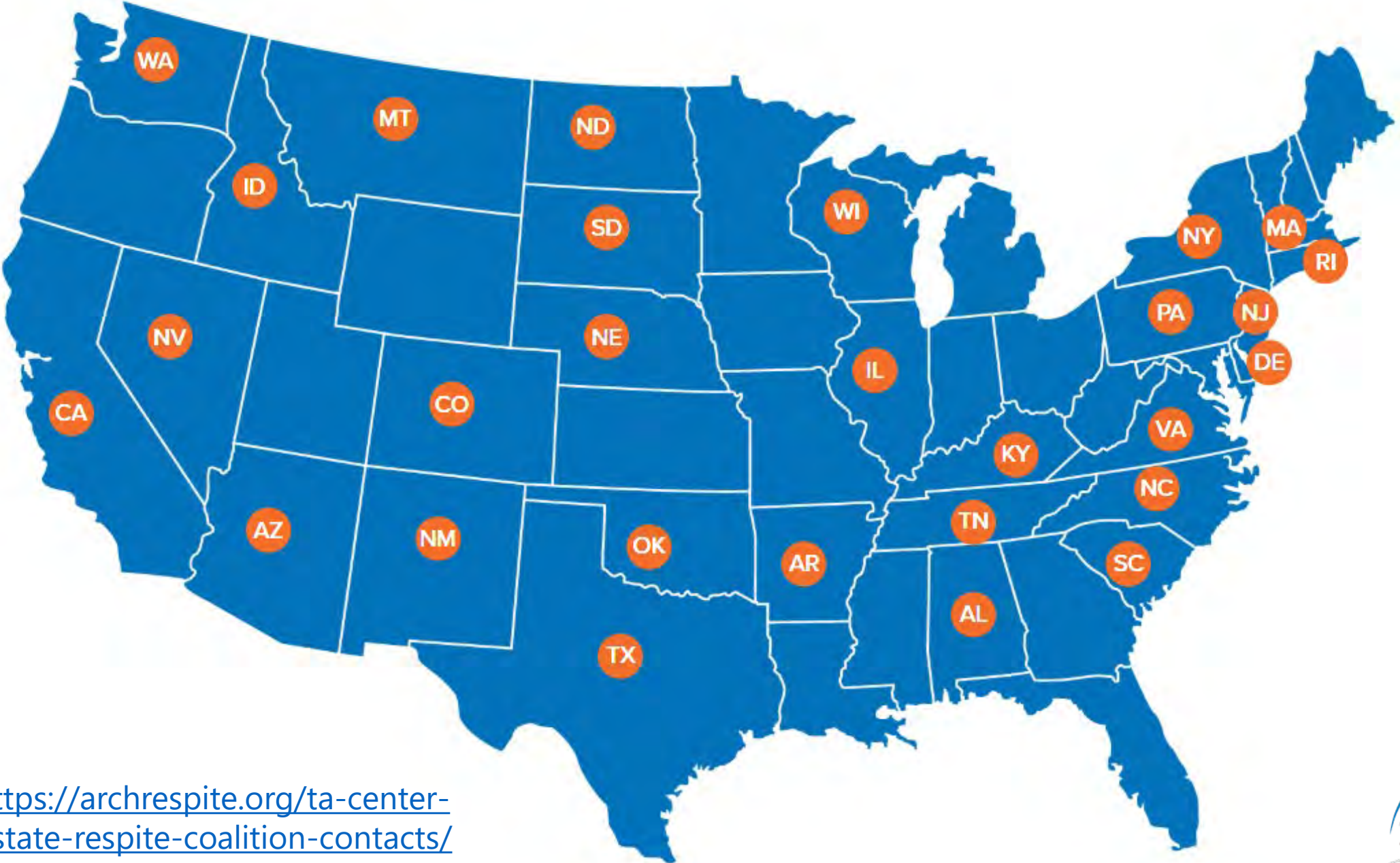
Federal Administration

US Administration for Community Living administers competitive state grants for these required uses of funds:

- ❑ Development or enhancement of State and local Lifespan Respite systems
- ❑ Planned or emergency respite for all ages
- ❑ Training and recruitment of respite providers/volunteers
- ❑ Provision of information to caregivers about respite services, and assistance in gaining access



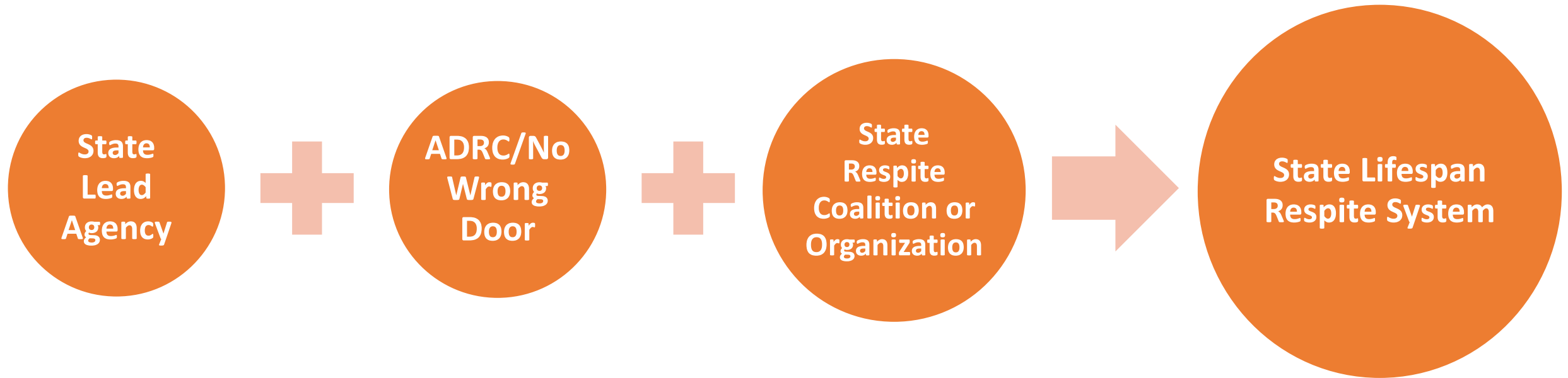
State Respite Coalition & Lifespan Respite Grantee Contacts



Map Link: <https://archrespite.org/ta-center-for-respite/state-respite-coalition-contacts/>



Lifespan Respite Systems Built on Collaboration



Role of State Lead Agency

- ❑ Program Administration and Implementation
- ❑ Program Oversight
- ❑ Contracts to Local Entities
- ❑ Assuring 25% non-federal match



Possible roles for the Aging and Disability Resource Center (ADRC)

- ❑ Outreach, public awareness and information dissemination
- ❑ Information and referral; options counseling for respite
- ❑ Serve on State Advisory Teams or Task Forces
- ❑ House respite registries and resources



Coalition's Significance to Lifespan Respite Program

- ❑ Brings representation of all ages and disabilities
- ❑ Brings caregiving and respite expertise and skills
- ❑ Ensures ongoing support, cohesion, and sustainability for the program



Lifespan Respite Overarching Aims

Systems Building

**Service Delivery and
Innovation**

Capacity Building

Sustainability



Systems Building Activities



Connecting families to respite

Respite registries, centralized databases, websites

Cross-agency collaboration

State Coalition building/Regional hubs

Public awareness and engagement campaigns

Service Delivery and Innovation



Self-directed Respite Vouchers

Volunteer and faith-based respite

Emergency/crisis respite

Respite for kinship families

Sibshops

Capacity Building Activities



Respite provider recruitment, training and retention

Minigrants to community and faith-based organizations for new services

Identification and promotion of informal or alternative respite options

Students as respite providers

Sustainability Planning & Strategies



Integrating respite into No Wrong Door, LTSS State Systems

Employing innovative fiscal strategies

Forging State agency fiscal partnerships

Employer Engagement

Documenting outcomes

Strengthening Coalitions to seek private funding and undertake legislative advocacy

Expanding reach of informal services and community supports

State Highlights

- State Summaries of Lifespan Respite Grant Activities
archrespite.org/lifespan-programs/state-lifespan-respite-grantee-activities
- In Support of Family Caregivers: Key Accomplishments of Lifespan Respite Grantees
archrespite.org/library/key-accomplishments-of-lifespan-respite-program-grantees



Lessons Learned

- It takes time....
- Build on model approaches
- Partnerships are essential
- Flexibility is key
- Performance measurement from day one
- Sustainability planning and focus are critical from the outset





ARCH Resources

Helping Caregivers Rest and Recharge

We assist and promote the development of quality respite and crisis care programs, help families locate respite and crisis care services, and serve as a strong voice for respite in all forums.

I am looking for...



Caregiver Resources

Respite Provider Resources

Website: <https://archrespite.org>

Policy and Advocacy

Respite Research

Resource Library



9 Steps to Respite for Caregivers



Issue Briefs



Respite for Individuals with Autism



In this Brief

- 1 Introduction
- 1 What is Autism?
- 2 Challenges Facing Individuals with Autism and their Family Caregivers
- 3 Benefits of Respite
- 4 Need for Respite
- 4 Barriers to Respite
- 5 Respite for Children with Autism
- 7 Respite for Adults with Autism
- 7 Federal Funding Sources for Respite
- 8 State Funding Sources for Respite
- 9 Private Funding to Support Respite Services
- 9 Considerations for State Lifespan Respite Programs, Partners and other Program Administrators
- 10 Considerations for Family Caregivers
- 10 Conclusion
- 11 Resources
- 12 References

Introduction

Autism is a neurological and developmental disorder that can cause significant social, communication, and behavioral challenges. Once thought to be a low incidence disability, the most recent report from the Centers for Disease Control and Prevention (CDC) says the condition now affects 1 in 36 children – a 211% rise over the 2009 estimate of 1 in 110.

For those individuals with Autism with significant functional support needs, it can be stressful for their families and result in feelings of isolation within their communities. The physical and mental well-being of parents, siblings, and other family caregivers, as well as a family's social relationships, finances, and overall stability can be affected. Families identify respite care as a basic need, with the need increasing as the child gets older. Respite care for families who have a child or adult with Autism helps maintain family stability, has been shown to reduce the probability of hospitalization, and may provide opportunities for the individual with Autism to participate in special activities.

This ARCH Fact Sheet is intended to provide an overview of useful information for respite providers who work with individuals and families affected by Autism. It is also meant to assist Lifespan Respite grantees and their collaborators by increasing their understanding of the unique needs of this population and their family caregivers. Such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. It is also intended to offer resources for family caregivers seeking to expand respite opportunities for themselves and others.

What is Autism?

Autism is a complex, developmental disability with a variety of symptoms that affect individuals in different ways. It knows no racial, ethnic, or social boundaries. People with Autism may have difficulties in communication and social understanding. They may also have unusual reactions to sensory input and may demonstrate what to some people might be considered to be inappropriate behaviors. Autism is now known to be more common than previously thought, affecting 1 in 36 children, and over 5 million adults. (CDC, *Data & Statistics on Autism Spectrum Disorder*, 2023; Dietz, et al., 2020).



Volunteer Respite: Roadmap to Resources



In this Fact Sheet

- 1 Introduction
- 1 Types of Volunteer Respite Opportunities
- 3 What Do Volunteer Respite Programs Look Like?
- 4 Respite Serving Diverse Populations
- 4 Successful Volunteer Recruitment Strategies
- 5 Recruiting Specific Groups of Volunteers
- 7 Screening, Selecting, Matching and Placing Volunteers
- 8 Training Respite Volunteers
- 10 Volunteer Retention
- 11 Risk Management for Volunteer Programs
- 12 Volunteer Respite Costs and Benefits
- 12 Resources

Introduction

Respite is temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. Any activity or time that provides safety, security, and care for loved ones with special needs, while also providing meaningful relief for the family caregiver, can be considered respite. The array of respite program models and services offer many opportunities for volunteers to contribute their time and talents.

Explore information and resources for recruiting, screening, training, and retaining volunteers to provide respite services to caregiving families in various settings. For a more in-depth discussion of these topics, and a step-by-step guide to starting a volunteer respite program, please see the [ARCH Volunteer Respite Manual: Creating Valuable Options for Family Caregivers](#).

Types of Volunteer Respite Opportunities

Respite can be provided in-home or out-of-home, with various types of providers and environments. Through the use of volunteers, respite programs can stretch limited resources to provide services to more family caregivers and care recipients. With appropriate training and staff supervision, volunteers can support almost any respite model and fulfill many roles.

Respite programs most frequently offer respite volunteer opportunities to provide direct care services to care recipients across the lifespan.

In addition to direct care volunteer respite roles, volunteers may provide program support by organizing and overseeing respite activities.

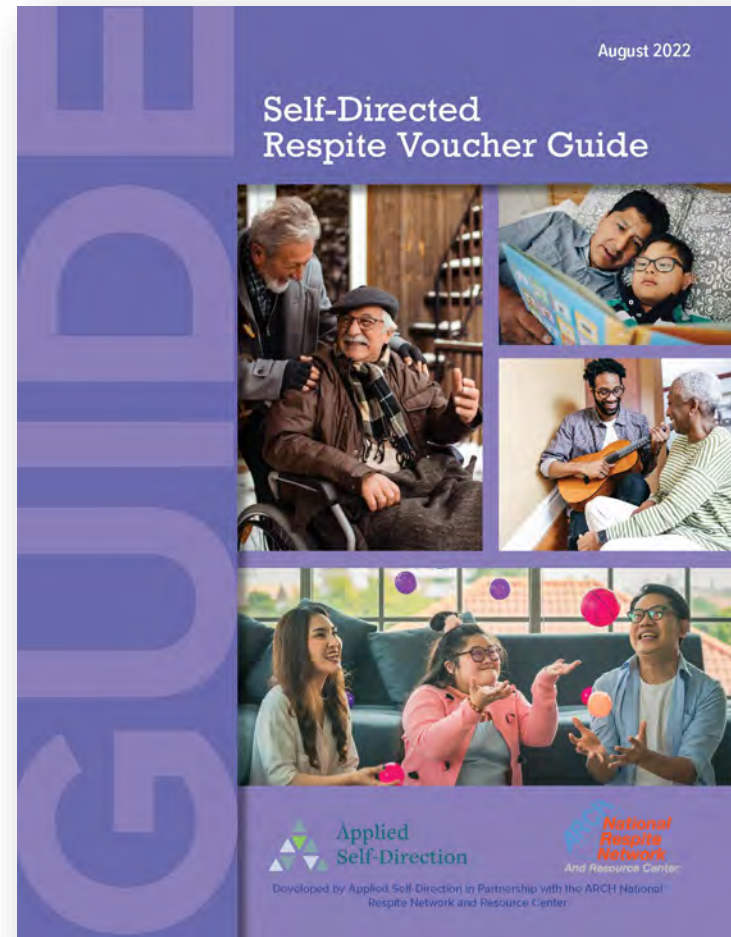
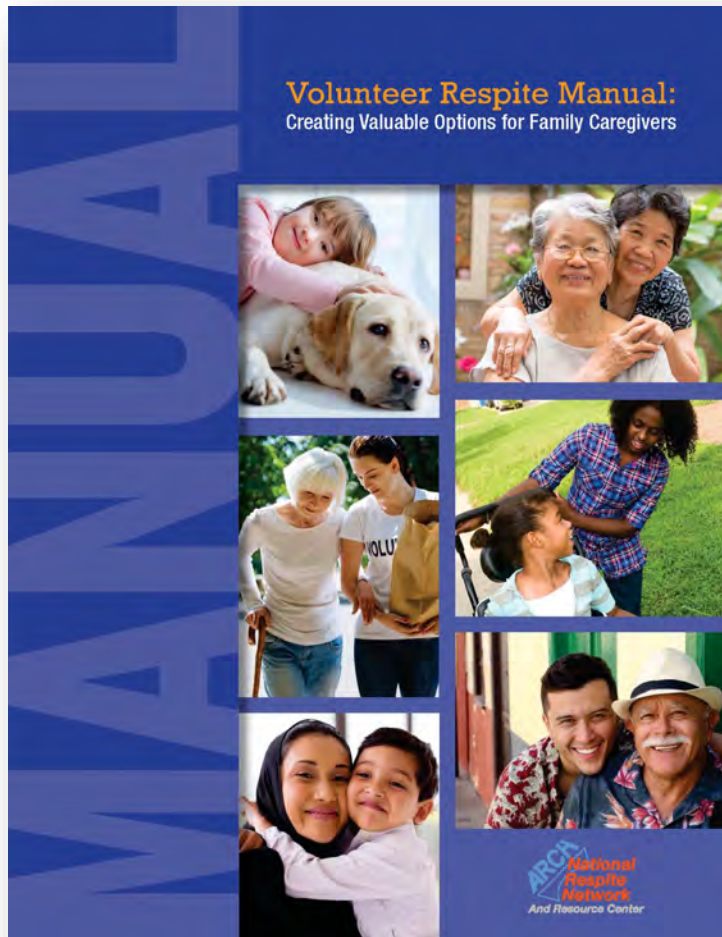
Volunteers may provide direct care and also carry out a variety of other tasks in programs such as day or overnight camps for individuals with special needs, adult day services, after-school programs, and park and recreation programs. Even facility-based respite, which can take place in residential facilities, crisis nurseries, group homes, assisted living, and nursing homes may be able to use volunteer support on some level.

Volunteers have potential to support many innovative models for respite program expansion and services. Examples include:

- **Activity/Event Respite:** Hosting a group event for individuals with special needs can offer a respite break for family caregivers. Volunteers can support and implement event respite programming. Respite events such as an afternoon of horseback riding for children with autism, or a lunch program for those with dementia, can provide a much-needed break for family caregivers.



Manuals and Guidebooks





Lifespan Respite Technical Assistance and Resource Center



Grantee and Coalition Contacts

Lifespan Respite 101

Grantee Activities

Learning Collaboratives

State Lifespan Respite Tools

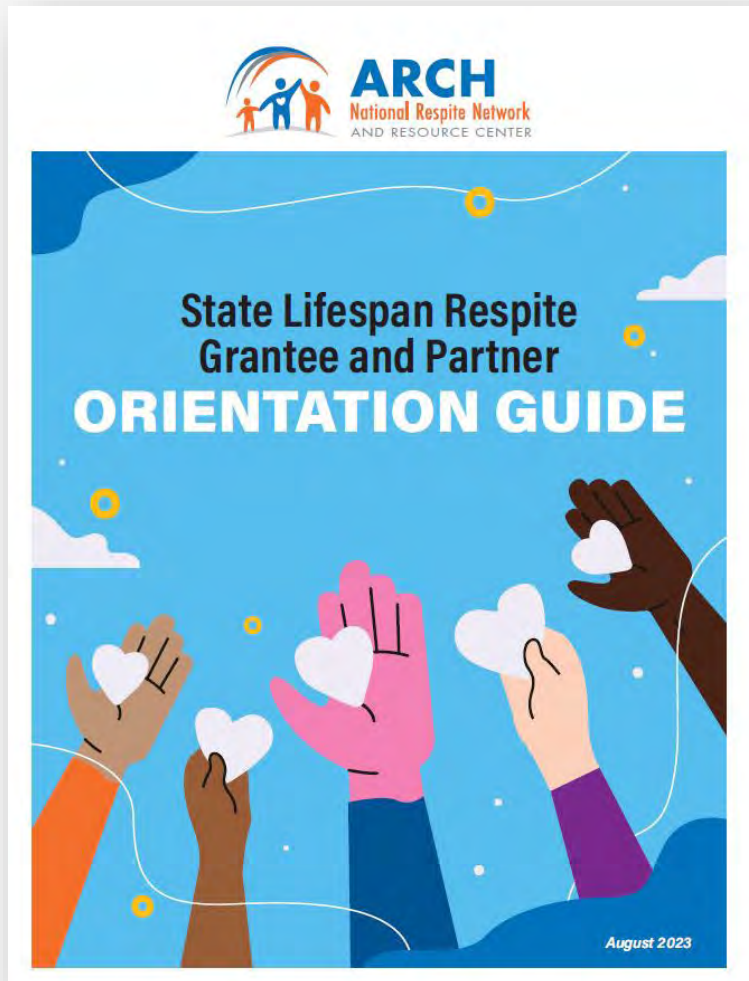
Respite Voucher Programs

Performance Measurement

Sustainability Tools

Link:
<https://archrespite.org/ta-center-for-respite/>

Lifespan Respite 101



- Lifespan Respite 101 Toolkit
- ACL Notice of Funding Opportunities
- Building State Respite Coalitions
- Orientation Guide

<https://archrespite.org/ta-center-for-respite/lifespan-respite-101>



Learning Collaboratives *(currently paused)*

- Volunteer and Faith-based Respite
- Respite Vouchers
- Sustainability Planning
- Performance Measurement
- Implementation of the National Strategy to Support Family Caregiver Learning Collaborative
- Students as Respite Providers

All Learning Collaborative meeting recordings, products and resources can be found at <https://archrespite.org/ta-center-for-respite/learning-collaboratives/>



Sustainability Resources

- Financing Strategies for Lifespan Respite Grantees, Partners, and Respite Providers
- 2025 Webinar Series on *Sustaining Respite*
- State Tools

Link: <https://archrespite.org/ta-center-for-respite/sustainability-tools>



Financing Strategies for Lifespan Respite Programs, State Respite Coalitions, and Provider Agencies



Ensuring Sustainability in Respite Services and Systems

Sustaining respite services, programs, and systems requires a thoughtful, multi-faceted, and often concurrent set of actions. Long-term success depends on intentional planning and strategic execution as well as ongoing monitoring and plan adaptations. These action steps include:

- Develop a comprehensive, written sustainability plan, monitor and revisit the plan, and revise as needed
- Engage caregiver, agency, program, community, and advocacy key partners and build strategic alliances
- Document start-up and implementation processes
- Mentor new leaders and plan for leadership transitions
- Collect and use needs assessment and performance data to target resources and guide decisions
- Monitor for duplication and service gaps across agencies
- Leverage in-kind resources and grassroots/community support
- Integrate existing technology effectively
- Maximize current funding sources and identify new ones

Each of these actions plays a critical role in supporting strong, reliable respite systems that can grow and adapt over time.

Focus on Financing: Strategies for Respite Sustainability

This last element – **financing** – is the focus of this tool, *Financing Strategies for Lifespan Respite Programs, State Respite Coalitions, and Respite Provider Agencies*. Five overarching strategies for pursuing financial sustainability are offered:

- **Make Better Use of Existing Resources**
- **Maximize Federal and State Revenue**
- **Create More Flexibility in Existing Resources**
- **Build Public-Private Partnerships**
- **Create New Dedicated Revenue Streams**



Additional Networking and Resource Opportunities

- Lifespan Respite Exchange
- Social Media
 - #LifespanRespite
- Funding Opportunity Alerts
- ARCH Quick News Update
- Webinars





ARCH Initiatives to Enhance Respite and Build Capacity





National Respite Care Provider Training

- Meets National Core Competencies for Entry-Level Respite Providers
- Field Tested in 10 States
- Training is available at no charge
- Access the Training and the Replication Toolkit

<https://archrespite.org/library/national-respite-care-provider-training-and-replication-toolkit>



Innovative and Exemplary Respite Services



- Annual National Call for Applications
- Database of I & E Services
- Innovative and Exemplary Respite Services Evaluation Initiative

Read More at

<https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services/>

Respite Research Initiative

- Committee for Advancement of Respite Research
- Respite Research Summit
- White Papers
 - *Measuring the Value of Respite*
 - *Recommended Common Data Elements*
- Respite Research Consortium Updates
- Searchable Annotated Bibliography

Read More at
<https://archrespite.org/research/respite-research-consortium>



For More Information



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Technical Assistance Center



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