Family Support 101: Understanding Policies that Support Family and Family Caregivers for Trainees

Respite: Policy, Practices and Innovation

AUCD
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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.
What is Respite?
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*
Types of Respite

- **Formal Services**
  - Home care agencies
  - Group Home, Adult Day Services or Childcare Centers
  - Facility-based
  - Community-based agencies

- **Informal Services**
  - Family and Friends
  - Volunteer or Faith-based
Public Programs

- Medicaid Waivers
- National Family Caregiver Support Program
- Other Federal Programs
- State Funded Respite Programs
- Lifespan Respite Care Program
Private Sector Options

- Disability Organizations
- Community-based Programs on sliding-fee scale
- Parent Cooperatives
- Free Volunteer or Faith-based Services
- Self-pay
Everyone Needs Respite!

- Reduces Stress
- Improves physical and emotional health
- Enhances relationships and reduces social isolation
- Care recipients benefit, too!
Respite: Too Little, Too Late

- Yet, 86% of family caregivers of adults are not receiving respite services at all.
- A significant percentage of caregivers of children with an unmet need do not receive respite (63% to 75%).
- Of those who use respite, they often receive too little, too late.
- Barriers to Respite
Enhancing Respite Practice
Core Competencies
Online Entry-level Respite Provider Training Curriculum
Field Tested
Find more information
https://archrespite.org/provider-resources/provider-training-resources/#TrainingAccordion-1
Lifespan Respite Care Program

Definition: Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
Self-Directed Respite Voucher Models

**Who can the families select to provide respite?**
- Family, Friends, Community Members
- Vetted Agencies

**Who receives payment?**
- Reimburse Family Caregivers
- Reimburse Agencies/Providers
Lifespan Respite Voucher States

[Map showing states with Lifespan Respite Voucher Programs]

Lifespan Respite Voucher Programs:
- **Red**: Lifespan Respite State with Self-Directed Respite Voucher Program
- **Blue**: Lifespan Respite Emergency Respite Vouchers only
LifeCourse Tools for Respite

Purposes are to provide:

- information on the importance of respite;
- tools for thinking about and planning for respite; and
- additional resources for finding respite in the community.

LifeCourse Respite tools can be found at archrespite.org/caregiver-resources/planning-for-respite/#tools or www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite
Respite and Caregiving Policy
National Strategy Goals

- GOAL 1: Increase awareness of and outreach to family caregivers
- GOAL 2: Advance partnerships and engagement with family caregivers
- GOAL 3: Strengthen services and supports
- GOAL 4: Ensure financial and workplace security
- GOAL 5: Expand data, research, and evidence-based practices to support family caregivers.
2022 Strategy lays out a framework for systemic caregiver supports, and identifies caregiver needs that require new legislation

- 350+ Federal actions from 15 federal agencies
- 250+ broad actions for states, communities and stakeholders with a “roadmap” of ideas
Respite Resource Guide

- Designed as an action guide for state agencies
- Produced by ARCH in collaboration with NASHP
- Examples align with 5 goals of the strategy

The Challenge
Despite the demand for this service, many family caregivers do not receive it. Challenges include a lack of trust of unknown providers to provide care, especially in homes; difficulty in finding and paying for quality providers; and rigid program policies that limit the types of respite providers (e.g., those that do not allow for family, friends, and known providers to provide respite).

A Historic Opportunity
The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) developed a National Strategy to Support Family Caregivers that is now ready for implementation. Released to Congress in September 2022, this comprehensive strategy identifies actions for the federal government to take and lays out actions for states, communities, health care systems, long-term support and service providers, researchers, employers, philanthropic organizations, and many others to support family caregivers. Respite care is a key component of this strategy.

State Action Guide
The ARCH National Respite Network and Resource Center created a Learning Collaborative of state administrators and their partners. In partnership with the National Academy for State Health Policy (NASHP), the Learning Collaborative created this roadmap for states that want to implement the respite actions identified in the National Strategy. The roadmap can support states interested in building or expanding respite care for family caregivers by offering the following policy strategies and promising practices.

https://supportcaregiving.org/respite-care/
Taking Congressional Action

- Urge Congress to ensure promise of **National Strategy to Support Family Caregivers** through **Act on RAISE**.

- Increase funding for the **Lifespan Respite Care Program** and the **National Family Caregiver Support Program**

- Support **Home and Community-based Services (HCBS) Relief Act (S.3118)** to strengthen the direct care workforce, decrease waiting lists for HCBS, support family caregivers.

- Advocate for **Alleviating Barriers for Caregivers Act (S.3109)**
Join us!

RAISE the Bar for Respite

Strategies to strengthen family caregivers

2024 National Lifespan Respite Conference • May 21-23, 2024 • Albany, NY