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

- Overview of Lifespan Respite Care Program
- National Picture of Self-Directed Respite Voucher Programs
- Wisconsin’s Caregiver Respite Grant Program *presented by Lisa Schneider, Executive Director Respite Care Association of Wisconsin*
- Oklahoma’s Lifespan Respite Voucher Program *presented by Aietah Stephens, Executive Director, Sooner SUCCESS*
Lifespan Respite Care Program

Definition: Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
Administration for Community Living awards grants to state agencies on a competitive basis. Since 2009, 38 states and DC have received at least one grant.

Map of Current Grantees and State Respite Coalitions: archrespite.org/ta-center-for-respite/state-respite-coalition-contacts/

Required Partners:
State Respite Coalition or Statewide Respite Organization
Aging and Disability Resource Center/No Wrong Door system
Lifespan Respite Grant Activities

Connecting families to respite

Outreach and Public Awareness

Recruiting and Training Respite Providers

Volunteer and Faith-based Respite

Promoting Informal Respite Opportunities

Self-Directed Respite Voucher Programs

READ MORE about Grantee Activities at: archrespite.org/ta-center-for-respite/grantee-activities-and-key-accomplishment/
Lifespan Respite Voucher States

- States with Lifespan Respite State with Self-Directed Respite Voucher Program:
  - AZ, CO, IL, NE, NV, OR, WA, WI

- States with Lifespan Respite Emergency Respite Vouchers Only:
  - AR, NC, TN

Note: The map shows the distribution of states offering Lifespan Respite Voucher Programs.
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 Program Characteristics

- All serve family caregivers of both children and adults with any condition
- More than half provide emergency respite vouchers
- Three fourths have no income eligibility requirement; only two use cost-sharing
- All target unserved or underserved caregivers
- Many made COVID flexibilities permanent
Self-Directed Respite Voucher Guide

and the

Self-Assessment Readiness Review Tool

developed in partnership with

**Applied Self-Direction**

[archrespite.org/library/participant-directed-respite-guidebook/]
Self-Direction in Respite Voucher Programs: Path to Person and Family Centered Care

An overview of Respite Care Association of Wisconsin’s Caregiver Respite Grant Program
RCAW’S Caregiver Respite Grant Program (CRGP) - Overview

- The CRGP is a highly self-directed program allowing maximal choice and control for families.
- The main goal is to increase the availability of respite for families and caregivers; and decrease the barriers to accessing these needed services, regardless of the acuity of the care recipient.
- This program is available across the lifespan, meaning children, adults, and older adults.
- It is designed to support the primary family caregiver in getting a break from caregiving duties.
- It supports primary caregivers who cannot be served by other Long-Term Care (LTC) waiver programs; or other caregiver support programs. However, we will approve an application for those who have either exhausted program funds or are on a program’s wait list.
- Family caregivers can apply for up to five (5) days of respite care that will occur within 30 days of grant approval. We also have an Emergency Respite Grant Program for emergency situations.
- Family caregiver can choose who they want to hire to provide one-on-one care for their loved one living with disabilities or special needs as long as they don’t live on the same property as the primary caregiver and care recipient.
RCAW'S Caregiver Respite Grant Program (CRGP) - **Specifics**

- RCAW is not a respite provider, nor does it employ any respite providers.
- RCAW pays the approved grant funds to the family caregiver (applicant), and they in turn are responsible for paying the respite care provider. However, if respite care is provided by an agency or facility-based program, we can pay them directly.
- Payment is generally issued after respite care services have been provided, but will make exceptions in unusual situations.
- Applicants need to provide their social security number. For those who received a cumulative of $600 or more in grant funds in a calendar year, RCAW must issue a Form 1099-MISC for that year.
- Family caregivers can reapply for this grant a few times a year, depending on funding availability. Currently they can apply every 60 days.
- There is currently no max amount that family caregivers can receive per year. Applications are approved based on the care recipient's acuity and respite care provider credentials provided the charges are in keeping with fair market service rates.
- There is no financial threshold for applicants to meet in order to apply.
RCAW’S Caregiver Respite Grant Program (CRGP) - Policy

- All applicants must have a valid email address and create a profile on RCAW’s grant portal.
- RCAW reserves the right to ask for additional information and supporting documentation from applicants when approving a grant request.
- Depending on the number of respite hours and respite provider chosen, overnight stipends may be required vs. an hourly rate.
- Applicants must complete an RCAW Eligibility Criteria Form and a Supporting Documentation Form each time they apply for a grant.
- After respite care services have been provided, the applicant must submit a grant report form attesting to services provided, amount paid, who the provider was, etc.
- Applicants must submit a completed Caregiver Experience Survey in order for applicants to reapply for a CRGP grant.
- RCAW reserves the right to deny CRGP applications, and applicants have the right to appeal using the Grant Denial Appeal Form. RCAW has established an appeal process.
Caregiver Respite Grant Program (CRGP) – 4-Step Process

**Step 1:** Applicant completes the Eligibility Criteria Form (ECF) and the ADRC or County completes the Supporting Documentation Form (SDF)

**Step 2:** Once the ECF and SDF have been completed and submitted to RCAW and all looks kosher, RCAW will notify the applicant via email along with a link to the grant application.

**Step 3:** Once RCAW receives the completed CRGP application, RCAW will notify the applicant if the application is approved via email with a link to the Grant Report that must be completed and submitted once respite services have been provided.

**Step 4:** Once RCAW receives the completed Grant Report, the applicant is sent a link to complete the CRGP Respite Experience Survey. (Applicants can not reapply if they do not submit this survey.)
CRGP SUPPORTS SELF-DIRECTION

- **Spending Limits:** Many voucher programs have a spending cap, with a maximum usable amount within a given period.
  - RCAW's CRGP has no maximum usable amount within a given period if it is in line with the care needs of the care recipient and market rate costs whether it's an individual or facility provider.
CRGP SUPPORTS SELF-DIRECTION

- **Time Limits:** Another common voucher characteristic is the imposition of a time limit in which it must be used. The main reason for this time limit is that it prevents unforeseeable accounting shocks in future time periods.
  - RCAW’s requires applicants to apply for respite that is going to occur in the next 30 days to better manage and spend funds in a timely manner.
CRGP SUPPORTS SELF-DIRECTION

• **Rate Setting:** The rates that participating caregiver applicants are allowed to pay their respite providers varies from program to program.
  
  • RCAW’s CRGP allows the caregiver to determine the rate to pay a respite provider, maximizing their choice and control and adhering to the principles of self-direction. If care is provided by an agency or facility, the rate is generally determined by that provider.
CRGP SUPPORTS SELF-DIRECTION

• **Consumer Feedback:** Applicants complete a satisfaction survey at the end of their CRGP respite experience.

  • RCAW collects satisfaction surveys from every applicant each time they apply. The next few pages have some of those results.
Q2: Overall, how satisfied or dissatisfied are you with the application process of RCAW's Caregiver Respite Grant Program?

- Very satisfied: 78%
- Somewhat satisfied: 16%
- Neither satisfied nor dissatisfied: 5%
- Somewhat dissatisfied: 0%
- Very dissatisfied: 0%
Q3: Did you find the processes involved in applying for assistance via the Caregiver Respite Grant program user friendly?

- Extremely friendly: 38%
- Very friendly: 35%
- Somewhat friendly: 27%
- Not so friendly: 0%
- Not at all friendly: 0%
Q4: Were you happy with the respite you received as a result of RCAW's Caregiver Respite Grant Program?

- A great deal: 81%
- A lot: 16%
- A moderate amount: 3%
- A little: 0%
- Not at all: 0%
Q5: What did you do during your respite time?

- Spent time with spouse/partner/other friends and family: 11%
- Spent time with other family members: 24%
- Participated in social/recreational activities: 16%
- Run errands: 3%
- Completed household tasks: 8%
- Had private time to relax, rest, read, pursue hobbies/interests: 16%
- Participate in physical activities or exercise: 0%
- Go to medical appointments/Tended to own health care needs: 3%
- Tended to own health care needs: 3%
- Other (please specify): 16%
Q6: How likely are you going to apply to the Caregiver Respite Grant Program again?

- Very likely: 95%
- Likely: 5%
- Neither likely nor unlikely: 0%
- Unlikely: 0%
- Very unlikely: 0%
Q7: What are the top three (3) challenges that you have as a family caregiver? Select up to three answers.

Financial: 44%
Feeling overwhelmed, anxious, depressed: 88%
Physical or other personal health challenges: 21%
Lack of sleep: 26%
Depression | Anxiety: 26%
Feeling isolated and lack of socialization: 41%
Strain on relationships with other family members: 38%
No challenges - all is good!: 0%
Q8: Did the Caregiver Respite Grant Program help or relieve any of the challenges you identified above?
Q9: Tell us about your respite experience?

• Appreciated the application was expedited given our unprecedented circumstances. Our family wished we would have known about the program sooner, but better late than never. Thank you for being so quick to process the request.

• Thanks for this much needed opportunity to spend time with my mother.

• It was so nice to be able to work on house DIY projects uninterrupted and not have to worry about the safety of my child at the same time. I knew my child was safe and being taken care of and having fun.

• I was able to go on a little trip with some dear friends of mine. I caught up on sleep and only had to take care of myself. I recharged my batteries and feel much better. Thank you!

• I was able to get away for a few days with some friends. It was nice to be able to unplug from caregiving for a little while. However, it also did make me realize just how much stress I am carrying as a caregiver and how difficult it really is to feel even a little relaxed. It is a challenge being always "on call”

• I am highly appreciative for this break and never take this gift for granted. It made me realize how awful my life, health and well being is, from being a caregiver for 15 years. There is no way out...feel like a shaking, trapped animal all of the time. Not ever human anymore. Again, many thanks for the relief. Just a big thank you, it was time our family desperately needed.
Thank you! Any questions?

Contact Info: Lisa Schneider, Executive Director
Respite Care Association of Wisconsin
Email: lschneider@respitecarewi.org
Phone: 608-222-2033
Lifespan Respite Grant Voucher Program in Oklahoma

AIETAH STEPHENS, MS
SOONER SUCCESS
The goal of this project is to expand, enhance, and ensure the sustainability of gap-filling respite services to Oklahoma family caregivers across the lifespan and disability spectrum.
Oklahoma Caregiver Coalition

- Meets Quarterly
- First meeting Sept 2016
- Chair, Vice Chair, Secretary, Communications, Respite Initiatives
- 200+ partners
- Subcommittees were developed from 2016 caregiver survey needs assessment:

Respite Locator - OK Cares

Need a Break?

Respite Locator

Respite programs are available to provide a temporary break from caregiving duties.
Helping Family Caregivers Connect to Respite and other resources in their Community
Who Is A Caregiver? For our purposes, a caregiver is an unpaid individual who provides ongoing care for someone with a chronic health condition or special health care needs.

- Spouse/Partner
- Friend/Neighbor
- Sibling
- Child caring for parent
- Parent of a child with special needs
- Grandparent or other relative raising a child
Caregiver Eligibility

- Caregiver must be 18 or older
- Provides full-time and unpaid caregiving for a loved one with a chronic health condition or disability
- Grandparent or other relative age 54 or younger raising a child as a full-time parent
- Does not have an annual household income over $125,000
- Does not receive respite services from other programs including, but not limited to foster care, Family Support Assistance Payment, OAA Title III-E, ODMHSAS Systems of Care funding.
Care Receiver Eligibility

- Age birth to 59 who needs help with activities of daily living in order to stay at home in the community, has a social security number (those 60 and older connect to Area Agency on Aging)
- Has a special health care condition/disability that requires 24/7 care
- Does not qualify for respite services or payments through any other program including, but not limited to, DHS Developmental Disability Services, SSI-DCP, OAA Title III-E, Advantage waiver program, Medicare-funded home health services or hospice.
Respite Provider

- Anyone the caregiver chooses such as a family member, friend, church member, center-based program or care center.
- Must be 18 or older, have a social security card.
- Lives outside the caregiver and care receiver’s home.
- **Paid after the care services have been provided.**
- Checks are mailed directly to the respite provider.
- The amount paid per hour is determined by the caregiver.
Program Elements

- Eligible caregivers receive $300 worth of respite vouchers.
- Caregivers have 3 months to use vouchers.
- Caregivers can reapply every 3 months.
- After an initial verbal screening
- Emailed an online application
- Caregivers complete the application and pre-voucher survey
- Voucher set is emailed
Data Collection

- Pre-voucher survey with the initial application.
- Post-voucher survey is also required to be completed by the caregiver. The post-voucher survey is emailed prior to.
- Data on funds spent by each caregiver is also monitored. Caregivers are responsible for any respite care that exceeds the $300 allowance.
- Data collected from the pre and post surveys is analyzed and reported.
“Thank you, this program has significantly reduced the stress in our home, strengthened or marriage and strengthen (loved one’s name) with the opportunity to be around other people.”

“This is such a great program and we are very blessed to be able to use these types of services”

“We are so thankful for this program. My husband and I where able to have date nights and enjoy one on one time knowing our grandchildren where being taking care of by those we know and trust.”

“I had to use an emergency respite voucher this last month. It has been so helpful having access to respite. We had a house fire and having respite care allowed someone to watch my daughter so she wasn't stressed by the construction or people coming in and our for repairs. So grateful for this program”
Educational Vouchers are also a part of this grant: Caregivers attending an educational event/conference and need to hire a respite provider are possibly eligible for a one time $100 full day voucher or a one time $50 half day voucher.

Emergency Vouchers are available for caregivers in a time crunch. They may need surgery themselves or need to travel to a funeral. A one time $250 voucher is available to eligible caregivers.

Ongoing efforts to support community Respite/Sibshops programs
Supporting Underserved Family Caregivers

- Provide applications, surveys and program materials in Spanish
- Launched the Minority Disability Coalition
- Host events with interpreter support
- Bilingual Team Members
Family Caregiver Conference

CAREGIVERS ROCK!
2023 Oklahoma Family Caregiver Conference

November 2
10:00 am - 3:00 pm

LEARN ABOUT:
- RESPITE
- WAYS TO RECHARGE
- STRESS MANAGEMENT
- SUPPORT ACROSS THE LIFESPAN

Conference Locations
Tulsa, Oklahoma City, Lawton, McAlester, Enid, Online

2023 Conference Pre Registration Form
(jotform.com)
Aietah Stephens, MS
(405) 271-5700, X47803
1-877-441-0434
aietah-stephens@ouhsc.edu
https://soonersuccess.ouhsc.edu/