

Lifespan Respite Learning Symposium

Updates from ACL

Lifespan Respite Care Program: RAISING the Bar for Respite Since 2009

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Before the Lifespan Respite Act

- There was Jill Kagan, Susan Janko Summers, and Casandra Firman
- Jill worked on the Hill (from 1983-1993) for the House Select Committee on Children, Youth and Families
- Jill wrote the legislation for Congressman George Miller that funded respite and crisis demos (including crisis respite programs) for children beginning in 1988
- Susan and Casandra helped start one of the crisis respite programs.
- In 1993, Jill was on the ARCH Advisory Committee, and formed the National Respite Coalition (NRC) to advocate for respite.
- NRC's principal objective was to help raise awareness of the value of respite and crisis care among policy makers in Washington DC.
- Before the federal program, there were programs in NE, OK, and OR

The Wheels of Progress Turn Slowly

Slow progress is the path that allows us to build a solid foundation, learn valuable lessons, and ultimately reach our goals more effectively and sustainably.

As we navigate our journeys, let's remember that every step, no matter how small, is a step closer to where we want to be.

Himanshu Salunke

Lifespan Respite Program: How it Started

- Lifespan Respite Care Program, enacted by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201)
- Funds were not appropriated to implement the Act until 2009
- Since 2009, ACL has awarded competitive grants to eligible agencies in 38 states and the District of Columbia plus the TA Center
- In 2009, we started with \$2.5M and in 2024, we are now at \$10M
- It was in 2016, when funding began to increase

Lifespan Respite Program: Oh, How it Grew

From 2016 to 2024, in just over 8 years, funding increased by \$7.64M or 324%!!!!

- 2016-2018 funding = \$3.36M
- 2019: funding = \$4.11M
- 2020: funding = \$6.11M
- 2021: funding = \$7.11M
- 2022: funding = \$8.11M
- 2023 & 2024: funding = \$10M

The Wheels of Progress Start to Turn

Program Enhancement Grants:

- Maximum grant awards increase slightly at first
- As the funding grows, maximum grant awards increase from \$265k to \$400k
- Project period grows from 3 years to 5 years but then, down to 4 years*^{*I'll explain}
- During pandemic, had funds to supplement grantees to continue to provide services

Grants to New States:

- Originally “forward-funded” – one pot of money to last 3 years
- Change to multi-year funding so receive federal funds each of the three years
- Revise NOFO to include “States Reestablishing Their Core Respite Infrastructures”

TA & Resource Center: Opportunity to work with Tawara Goode to develop [Cultural and Linguistic Competence Assessment for Respite Organizations \(CLCARO\)](#)

Progress Continues

All Grantees:

- With the release of the [2022 National Strategy to Support Family Caregivers](#), ACL added requirements for grantees to focus on respite recommendations

ARCH, as part of TA & Resource Center:

- Just months after “Strategy” released, ARCH releases “[Policy to Practice Brief](#)”
 - Purpose 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.
- Starts “[Implementing the National Strategy Learning Collaborative](#)”
 - Product: “[State Lifespan Respite Grant Activities Aligned with the National Strategy's Goals and Outcomes](#)” - documents possible strategies & actions that states have taken or plan to take

A Unique Opportunity for Progress

- In 2020, ACL issued a 3-year, forward-funded grant award to complement the work done by TA & Resource Center
 - Grantee: National Association of State Health Policy (NASHP)
 - Partners: ARCH and the Respite Care Association of Wisconsin
- Three main goals/objectives:
 1. Increase respite workforce recruitment, training and retention
 - **Respite Care Provider Training (RCPT)**: field-tested a competency-based online respite provider training curriculum for entry-level respite providers in 10 pilot sites.
 2. Build state-based framework and roadmap for respite system planning and development
 - **Respite Summit**: 16 state teams and federal officials from eight agencies for a peer-to-peer learning exchange on innovative models, strategies, and policies to increase access to high-quality respite care services.
 3. Enhance approaches to help caregivers and families develop or strengthen their own natural support systems.
 - **Respite Resource Guide**: ARCH Learning Collaborative of state administrators and their partners Roadmap for states that want to implement the respite actions identified in the National Strategy.

2020 Reauthorization of Program

- Lifespan Respite Care Reauthorization Act of 2020” (“short title”)– Added Section 2904, “Data Collection and Reporting” (Signed into law on January 5, 2021)
- Through an Act of Congress, ACL was now allowed, to use Lifespan Respite funds to develop and disseminate a program-wide data collection and reporting tool
- The work began quickly but took many, many months to complete
 - Worked with ACL Office of Performance and Evaluation and their contractor, RTI
 - Reviewed other data collection tools for formatting ideas
 - Met with grantees, in multiple ways, to gather input on what collecting now
 - Before OMB approval process, asked grantees to provide feedback/comments on draft materials – didn’t send to OMB until all feedback was incorporated

New Data Collection Tool – Overview

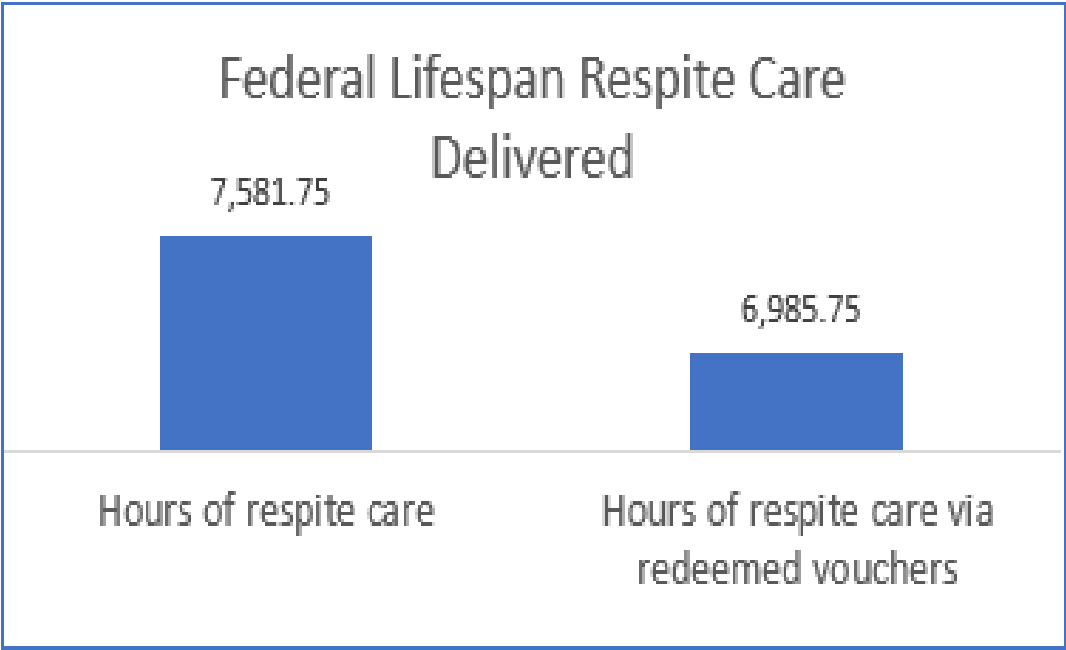
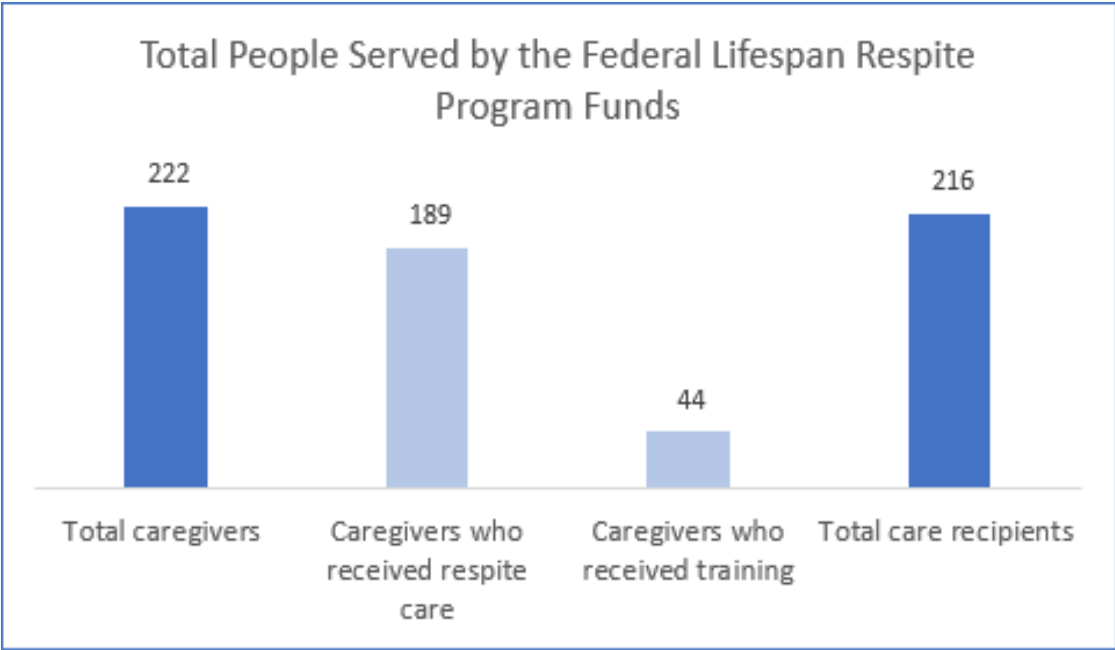
- Approved by Office of Management and Budget (OMB) in March 2023
- Eight new grantees funded in 2023 are the first to use this tool for reporting data
 - The data tool that must be used and cannot be reformatted is in Excel and provided by ACL.
 - Excel spreadsheet has formulas in it to ensure, where appropriate, numbers match
 - A User Manual and training is provided to all grantees before use
 - Excel spreadsheet submitted with each semi-annual report through GrantSolutions
- States currently required to use the new data tool: AZ, DE, ID, NC, RI, SC, TN, WA

Data Collection – Just the Basics

Five sections comprise the Lifespan Respite Program Information and Data Collection Tool:

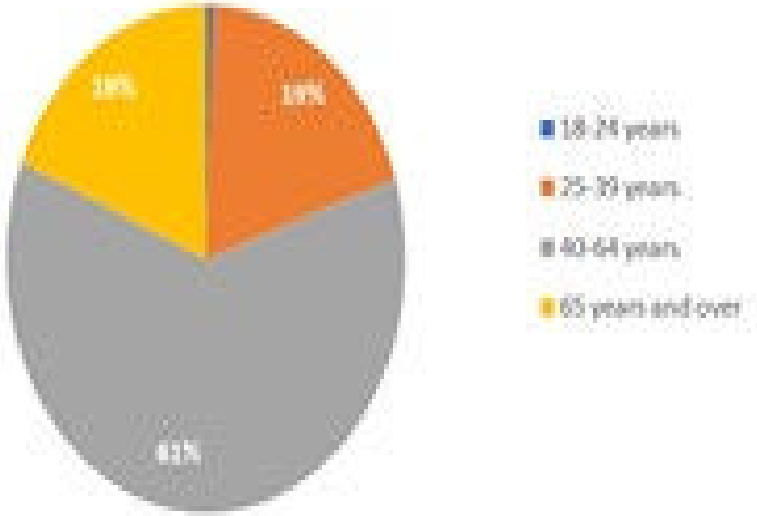
1. Counts of Care Delivered (aka Care Services Delivered)
2. Caregiver Demographics
3. Care Recipient Demographics
4. Respite Training/Provider Awareness (or Access to Respite Program)
5. Lifespan Respite Funding Match and Coalitions

Preliminary Aggregate Data – Care Services Delivered (1)

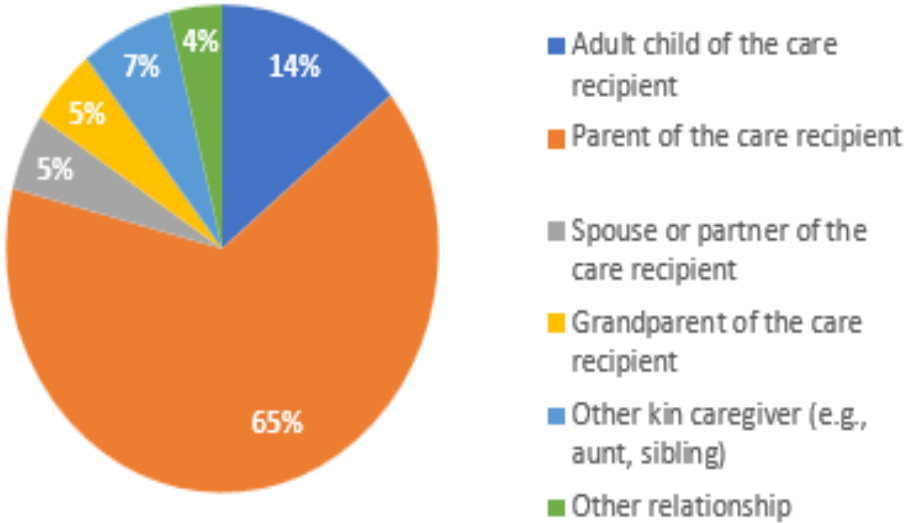


Preliminary Aggregate Data – Caregiver Demographics (2)

Caregiver Age

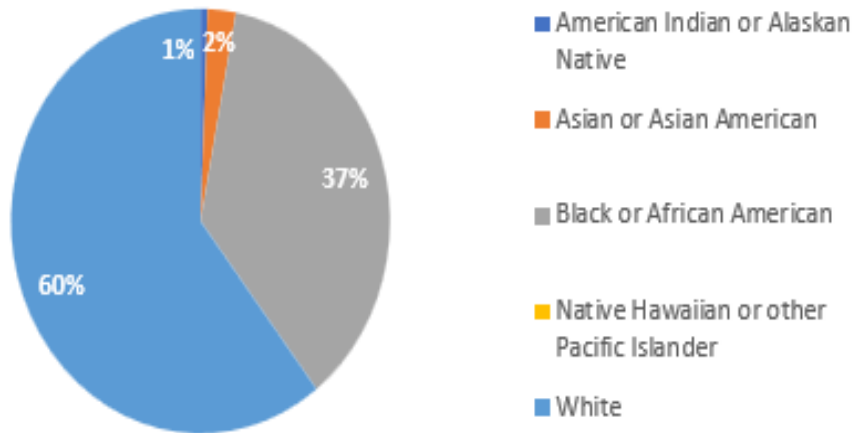


Caregiver Relationship to Care Recipient

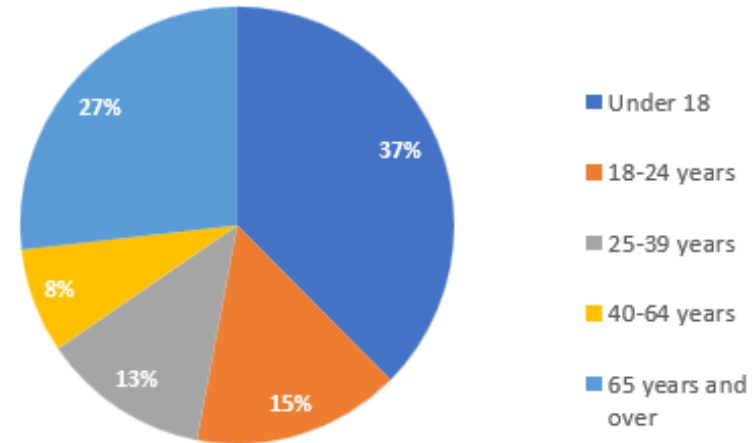


Preliminary Aggregate Data – Care Recipient Demographics (3)

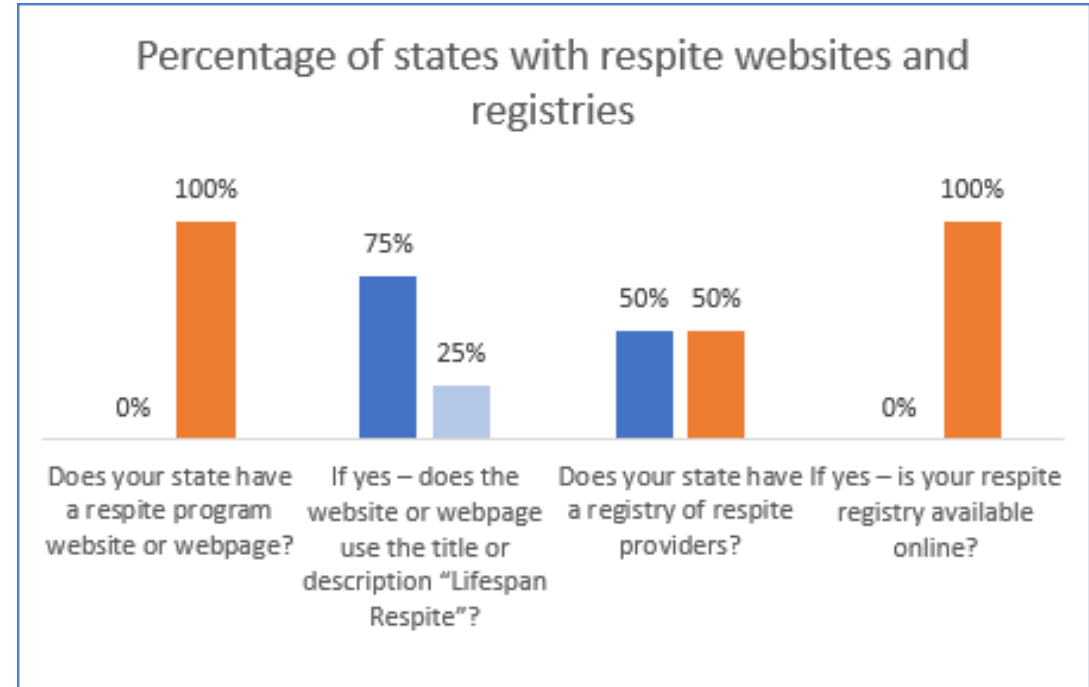
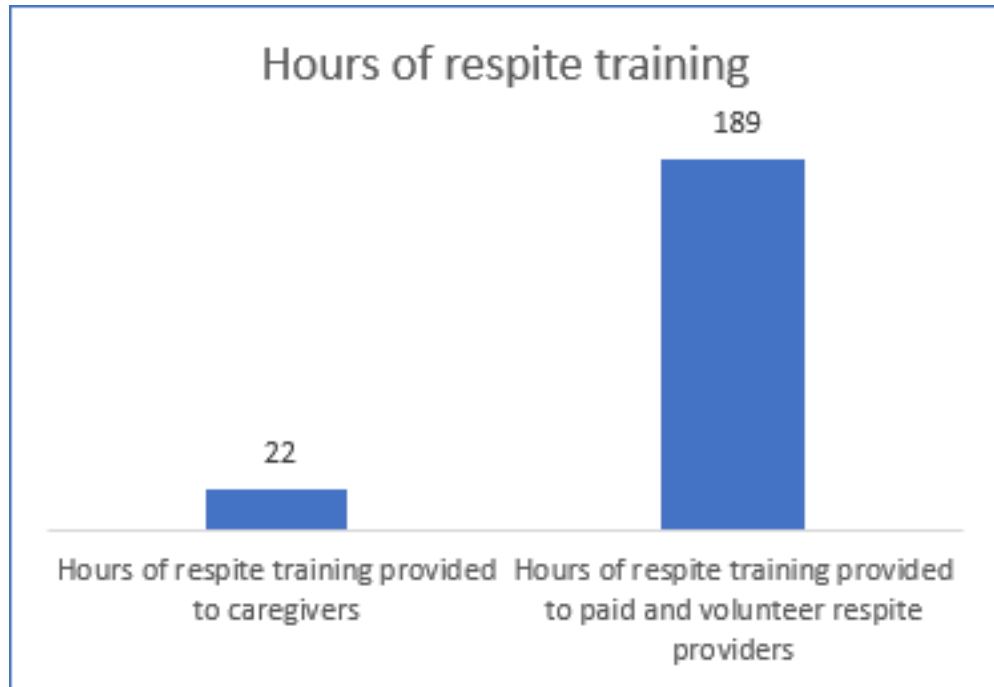
Care Recipient Race



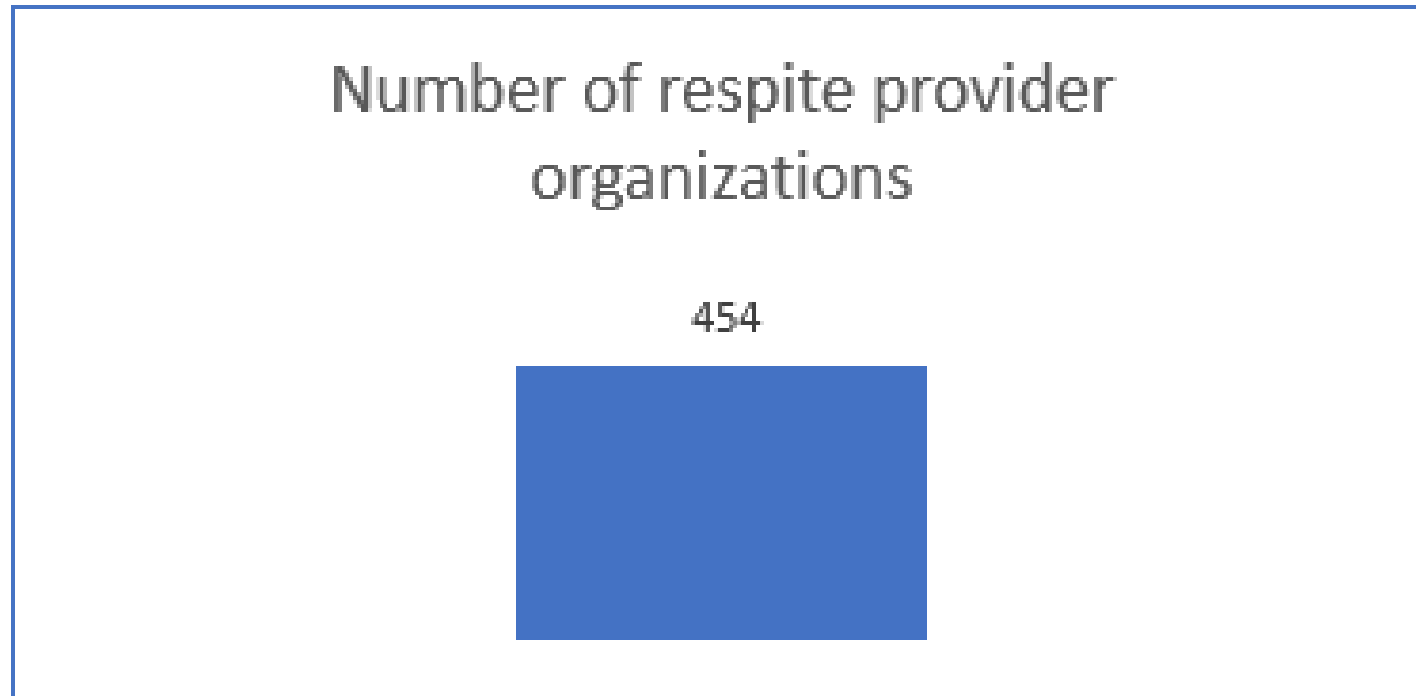
Care Recipient Age



Preliminary Aggregate Data – Respite Training/Provider Awareness (4)



Preliminary Aggregate Data – Lifespan Respite Program System and Providers (5)



National Technical Assistance to Kinship and Grandfamilies

GRANTEE: Generations United

WEBSITE: <https://www.gksnetwork.org/>

GOAL: Measurably increase the capacity and effectiveness of states, territories, tribes/tribal organizations and nonprofit and other community-based organizations to serve and support kinship and grandfamilies

OBJECTIVE: Work across systemic and geographic boundaries to better support grandparents, other relatives, and close family friends and the children they raise.

ACTIVITIES:

- Develop and provide technical assistance, resources, and training related to health promotion (including mental health and substance use disorder treatment), education, nutrition, housing, financial needs, legal issues, disability self-determination, caregiver support, and other issues across systems to more effectively support kinship and grandfamilies.
- Identify or foster the development of evidence-based, evidence informed, and exemplary practices or programs and propose approaches for supporting their implementation, scaling and replication.

Any Questions?

I'm so excited to be here!!!