A logo with green leaves

Description automatically generated**Lifespan Respite WA (LRW) Coalition**

**Purpose:** Organizations and individuals working together for combined action for respite services to improve the lives of **unpaid** family caregivers.

**LRW Website**: <https://www.lifespanrespitewa.org/>

**Link to the Coalition Webpages:** <https://www.lifespanrespitewa.org/lifespan-respite-coalition/>

**Quarterly Meetings on the 4th Tuesday at 11 am PT in January, April, July, and October**

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**January 23rd Agenda & Notes:**

**Introductions, History, and Purpose**

All attending shared their name, if a current/former unpaid caregiver, and/or any organization/agency affiliation.

The meeting began with Roslyn Alber, sharing the agenda and the historical timeline of Lifespan Respite in WA for unpaid caregivers [see slide deck]. Highlights from the timeline include….

* 1960 respite programs exist in the United States
* 1980 the Vanessa Behan Crisis Nursery hosting a national forum in Spokane, WA
* 1989 Funding was secured for demonstration grants and by the state legislature
* 1990 [ARCH National Respite Network & Resource Center](https://archrespite.org/) provides national training & technical assistance in developing statewide respite systems and in serving caregivers of persons of all ages and conditions.
* 2002 The Respite & Crisis Care Coalition of WA begins!
* 2012 New name – Lifespan Respite WA (LRW)
* 2018 PAVE is contracted for LRW

***New* Purpose Statement:** Organizations and individuals working together for combined action for respite services to improve the lives of **unpaid** family caregivers.

Discussion among those attending included some areas of clarification for us as a coalition.

* Focus is statewide in WA.
* **Unpaid caregivers.**
* Caregivers can be someone’s spouse, child, friend, family member, etc.
* Care recipients experience a disability.

Some of us may be affiliated with, align, and/or support organizations that support specific disabilities (e.g., intellectual, and developmental disabilities or IDD, brain injury or traumatic brain injury/TBI, spinal cord injuries, etc.). Lifespan Respite WA (LRW) is about unpaid family caregivers in Washington State. These unpaid family caregivers can care for individuals with any type of disability. By unpaid, LRW means family caregivers who do not receive funding to provide care.

An example: a family caregiver of an individual with intellectual and/or developmental disability (IDD), and that individual is deemed eligible for services from Developmental Disabilities Administration (DDA), **but** who is on the No Paid Services Caseload (NPSC). At any time, there are between 12,000 and 14,000 individuals on the NPSC who are potentially customers of LRW.

**National Strategies for Unpaid Family Caregivers & Kinship**

An overview of the national strategies:

Goal 1: Increase awareness & outreach.

Goal 2: Advance partnerships & engagement with family caregivers

Goal 3: Strengthen services & supports.

Goal 4: Ensure financial & workplace security.

Goal 5: Expand data, research, & EBP

**Reflections of how the strategies connect with our work in WA include:**   
Goal 1:

1. Everyone should know about family caregivers and positive and negative impacts of family caregiving both in the family and in the larger society
2. Family caregivers will identify as family caregivers to realize that supports exist
3. Outreach needs to be accessible, and linguistically & culturally competent/appropriate
4. Outreach to professionals across a wide range of sectors to improve their ability to identify family caregivers and to support them/steer them to supports
5. Family Caregiving and caregivers embedded in planning at all levels of government: federal, state, territorial, tribal, local

Goal 2: mostly about professionals in all fields, but mainly healthcare

1. Recognize family caregivers as essential partners of the *care teams of the person(s) to whom they provide care (trainings for advocacy to interact w care teams)*
2. Professionals: When appropriate, identify services and supports for caregiver needs using evidence-based assessments
3. Educate professionals as in Goal one

Goal 3: This is where our Coalition organizations and individual members come in:

1. Person/family centered, trauma informed, culturally appropriate and accessible services and supports to ALL family caregivers, including rural and underserved
2. Family caregivers can obtain respite services that meet their unique needs
3. Evidence based education, counseling, peer supports are available
4. Innovative tools and technology assists family caregivers in their roles
5. Trained volunteers
6. Family Caregivers have skills and tools needed to prepare for future needs of person cared for
7. Agile, flexible, well-trained direct care workforce

Goal 4: Reaching out to employers, trainings in advocacy for caregivers:

1. Leave programs, discriminations protections, tax credits: Fed and State Gov
2. Supporting legislation for those, advocacy training
3. Employee-centered flexible workplace policies and practices
4. Access to and use of financial education and advance planning tools (identify and provide)
5. More affordable LTSS (WA Cares)

Goal 5: There is now a National Technical Assistance Center through ACL to support national-level research.

Coalition members can consider sharing data, work on collating and combining useful data, and also think about capturing more data!

*Visit* [*the Administration for Community Living (ACL) 2022 National Strategy to Support Family Caregivers*](https://acl.gov/CaregiverStrategy) *webpage.*

*Visit* [*the Administration for Community Living (ACL) Supporting Grandparents Raising Grandchildren*](https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0) *webpage.*

**Overview of the New Grant and the Deliverables**

Dana Allard-Webb provided the following work plan for the new grant inviting all to ***share their insights***, wisdom, and **invite others, especially unpaid caregivers, to join our coalition**.

**Lifespan Respite Washington Grant Workplan 2023-2027: *Note: the workplan aligns directly with the National Strategy to Support Family Caregivers!***

1. **Strengthen Services and Supports for family caregivers:**
   1. Partner with ALTSA Paid Workforce Team to increase direct care workforce.
   2. Training curriculum development for tribal direct care workers and TBI family caregivers using person centered approach
   3. Use lessons learned to expand tribal voucher pilot as template for other tribes in Washington
   4. Meet with diverse caregiver populations; LGBTQ2+, TBI, DD, Kinship, dementia to learn about needs and issues
2. **Achieving greater awareness of and outreach to family caregivers:**
   1. Use analyzed LRW data to focus services in target populations and areas.
   2. Partner with Area Agencies on Aging and Spanish speaking Kinship Navigators to do outreach to increase participation in LRW services.
   3. Work with WA Cares to increase knowledge of respite vouchers through LRW
3. **Advance partnerships and engagement with family caregivers**:
   1. **Reorganize State-Wide Coalition** to include unpaid family caregivers and pay caregivers and community champions to participate. Include leadership from relevant organizations
   2. Collaborate with Tribal and other underserved communities to advance the importance of unpaid family caregivers and their need for respite and other self-care supports
   3. TBI Family caregiver skill share training project including modules for diverse populations.
4. **Improve financial and workplace security for family caregivers**
   1. With WA Cares, develop a guide for family caregivers explaining the importance of respite, other supportive services and self-care
   2. Meet with DSHS insurance provider Health Care Authority
   3. Survey caregivers, care receivers and service providers for needs, improvements and service gaps
   4. Meet with major WA employers to imagine respite and other benefits for their unpaid family caregiver employees
5. **More data research and evidence- based practices to support family caregivers:** 
   1. Gather Kinship data from Navigator evidence-based program
   2. PAVE- collect data to understand and target underserved populations in WA
   3. RDA Data Analysis (avg. time PAVE spends person centered time with family caregivers.)

**Wrap-up & Next Steps…**

* **Share information to join our coalition with those you know, especially unpaid caregivers.**
* **Read and share the notes from this meeting!**
* **Join the next LRW Coalition Meeting for all or any part of it: April 23rd at 11 am PT**