

Respite in Washington State:

**"A Beacon of Hope
in the Storms of Life"**





www.lifespanrespitewa.org

Panel

Linda J. Porter, LRW / PAVE

Dana Allard Webb, DSHS/ALTSA/HCS

Amy Knapton Vega, Vanessa Behan Crisis Nursery

Plan today

Framework / brief history of LRW

Respite programs in WA

Lifespan Respite's role in respite

Future aspirations



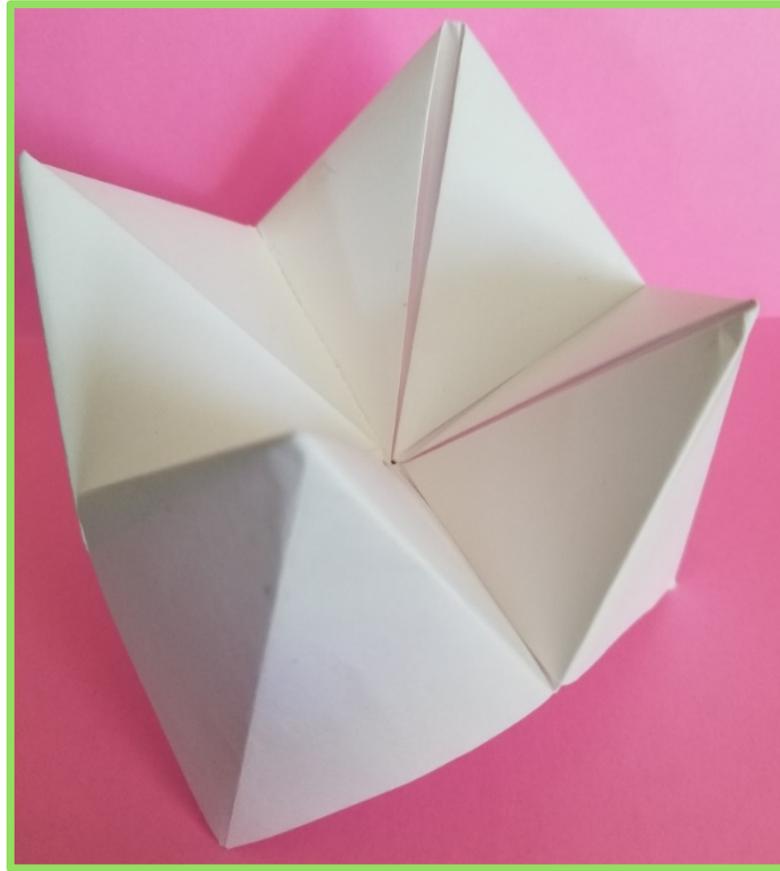
Collective Learning: Respite programs respond to caregiver trends

- Significant % of family caregivers report physical and/or mental health problems.
- Caregivers report chronic conditions at twice the rate of non-caregivers.
- Preventing their health problems save \$\$ in reduced hospitalizations, doctor visits, and work absences.

For every
\$1,000 spent on
respite related
to autism...

...there was an 8% reduction in
the in the odds of hospitalization
60 days later.

Fun Group Activity:



Fortune Teller

Historical Perspective

1980's to:

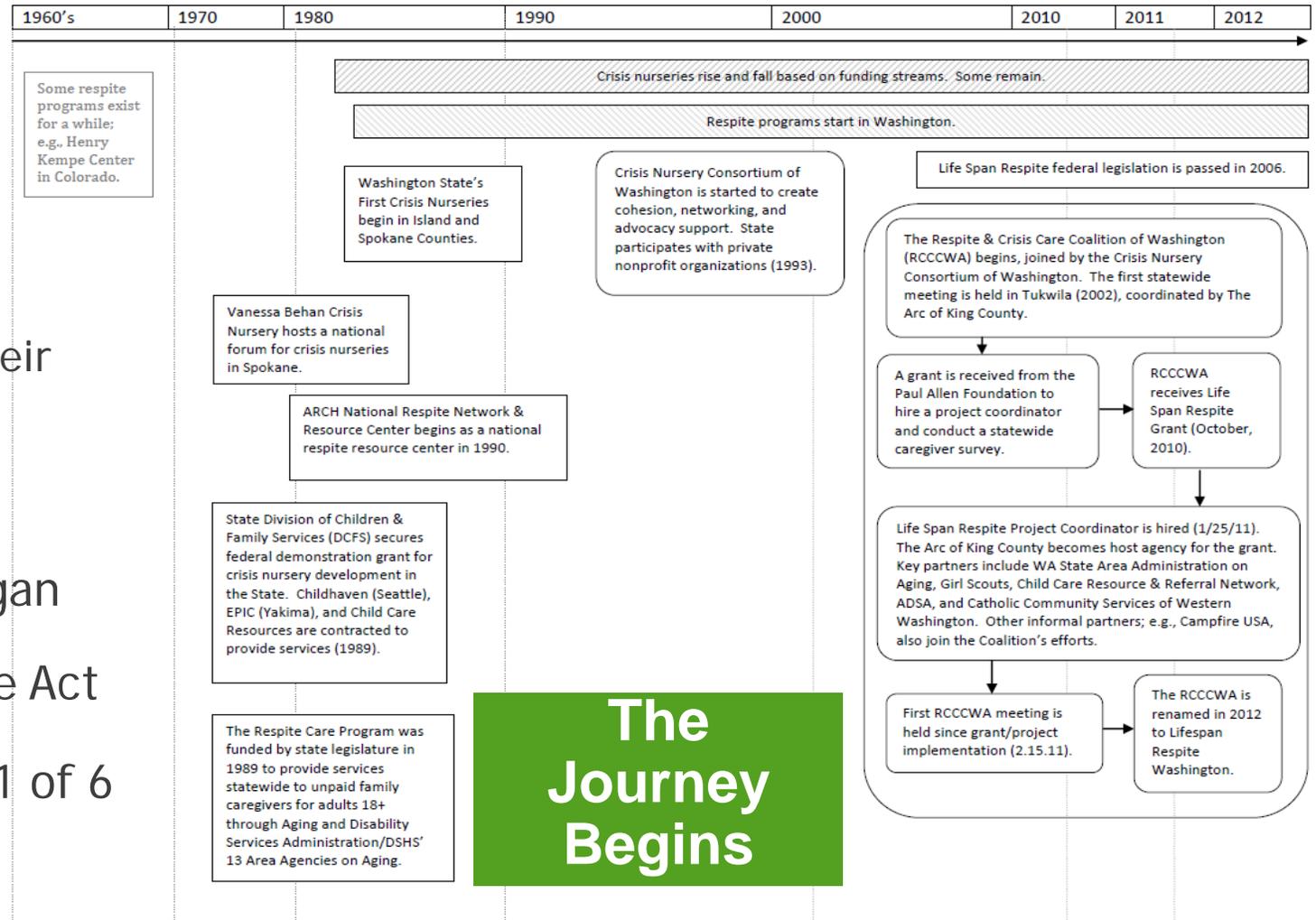
- Keep families intact and in their own homes
- Prevent abuse and neglect

2002 - Lifespan Respite WA began

2006 - Federal Lifespan Respite Act

2010 - Lifespan Respite Grant 1 of 6

HISTORY of RESPITE & CRISIS CARE in WASHINGTON





LIFESPAN RESPITE MANDATE	NATIONAL	WA STATE
Meet needs across the lifespan, birth through old age	✓	✓
Develop person-centered respite options for caregivers...	✓	✓
... <u>and</u> care receivers	✓	✓
Easy to access services	✓	✓
Coordinate systems of accessible, community-based respite	✓	✓
Map out available respite options	✓	✓
Serve the underserved	✓	✓
Create a respite coalition		✓
Develop a respite voucher program		✓
Respite Summit		✓

Dana Allard-Webb

Family Caregiver Support Program
Aging and Long-Term Care Administration
Lifespan Respite Grant Director
allardr@dshs.wa.gov

PLUS...

- ▶ Veterans Administration
- ▶ Exceptional Family Members Program
- ▶ Special Needs/Conditions Respite; e.g., American Parkinson's Disease Foundation
- ▶ State Children, Youth and Families - Foster/Kin Care Respite
- ▶ Crisis Nurseries
- ▶ Lifespan Respite WA voucher program--*as the payor of last resort*

Elizabeth Dole Foundation,
[Hidden Heroes website](#)
for caregivers

Respite Options in WA

(sample document to download from LRW website)

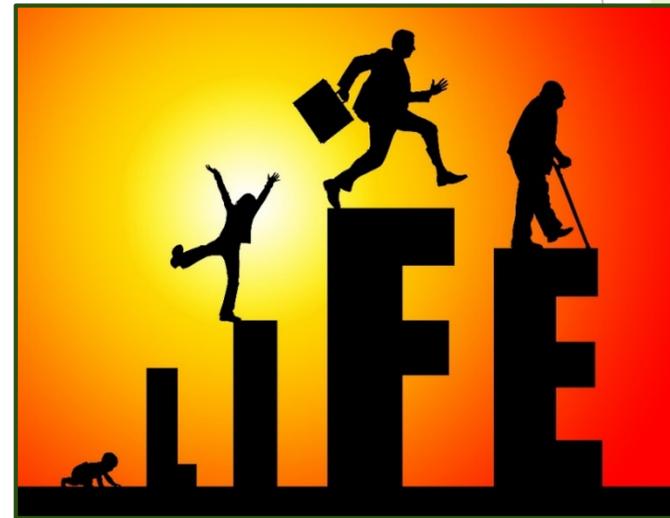
WA STATE RESPITE PROGRAM OPTIONS				
	Name of Program	Eligibility	Funding and Costs	More Information/Contact
Lifespan Respite Washington	Lifespan Respite Washington (adults)	<p>Unpaid caregiver who provides 40+ hours/week of care, support.</p> <p>Caregiver or the person cared for is not enrolled in a respite or Medicaid personal care program.</p> <p>Care is provided to someone with a qualifying special need.</p> <p>18 years of age or older and needs care/supervision to:</p> <ul style="list-style-type: none"> - Meet basic needs; - Prevent physical self-injury or injury to others; or - Avoid placement in an out-of-home, long-term care setting. 	<p>Funding Source: Grant</p> <p>Funding Amount: Limited to \$1,000</p> <p>Cost to Participate: N/A</p>	<p>Application</p> <p>Contact: Linda Porter Phone: 425-740-3788 Email: lporter@wapave.org</p>
	Lifespan Respite Washington (children)	<p>Unpaid caregiver who provides 40+ hours/week of care, support.</p> <p>Caregiver or the person cared for is not enrolled in a respite or Medicaid personal care program.</p> <p>Care is provided to someone with a qualifying special need.</p> <p>Less than 18 years of age who requires care/supervision beyond what is typically required to:</p> <ul style="list-style-type: none"> - Meet basic needs; or - Prevent physical self-injury or injury to others 	<p>Funding Source: Grant</p> <p>Funding Amount: Limited to \$1,000 per qualifying child</p> <p>Cost to Participate: N/A</p>	<p>Application</p> <p>Contact: Linda Porter Phone: 425-740-3788 Email: lporter@wapave.org</p>
Developmental Disabilities Administration	Overnight Planned Respite	<p>DDA enrolled individual who is at least 18 years of age or older. The individual must live in the family home or with a non-paid caregiver.</p>	<p>Funding Source: State Dollars</p> <p>Funding Amount: Up to 14 days per calendar year</p> <p>Cost to Participate: N/A</p>	<p>Participation does not impact assessed DDA waiver respite amounts.</p> <p>Contact: Local DDA Office and/or your assigned Case/Resource Manager</p>
	Dedicated Respite	<p>DDA enrolled individual who is 18 years of age and younger or between the ages of 18-20 and still in school. The individual must live in the family home or with a non-paid caregiver.</p>	<p>Funding Source: Regional DDA Budgets</p> <p>Funding Amount: Varies depending on Region</p> <p>Cost to Participate: N/A</p>	<p>Participation does not impact assessed DDA waiver respite amounts.</p> <p>The service is only available in Regions 2 and 3.</p> <p>Contact: Local DDA Office and/or your assigned Case/Resource Manager</p>

[Respite Program Options - PDF](#)



- Pilot started in 2014.
- Available for all ages across the lifespan.
- Fills gaps when respite cannot be used through another program.
- Use registered agency for respite.
- Meets the needs of both care partners.

Voucher Program





FIND RESPITE VOUCHER FACTS

ABOUT VOUCHER PROGRAM SERVICE PROVIDERS RESPITE CARE RESOURCES NEWS & EVENTS



Welcome to Lifespan Respite Washington

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers caring for that child or adult.

Respite is provided informally or in a more structured way through programs based on a variety of eligibility criteria. Some respite programs may utilize an available bed in a healthcare facility for families who require extended respite options for a family member or friend requiring skilled care.

Some services may be available to families through formal, often publicly funded, programs or may be available to families through informal networks. Respite is available in a variety of settings and has specific eligibility criteria. Some examples are:

- parent cooperatives
- caregiver support groups
- voluntary relief provided by family or friends, or
- cash subsidies from states to purchase respite through relatives and friends.

APPLICATION INFO

If you are seeking respite :

[Application if you are seeking respite](#)

Information for Respite Provider Agencies (RPA):

[RPA Applications](#)

[Policies and Procedures](#)

[Interagency Agreement](#)

www.lifespanrespitewa.org



Up to \$1,000 of respite

In-home supports

- medical care
- direct care for daily living activities
- companion care
- light housekeeping and meal-making

A simple application process video





Eligibility Requirements - Caregiver

- ▶ Unpaid family caregivers
 - Family, friend, or neighbor
- ▶ Provides 40 or more hours per week
 - Direct care
 - Monitoring, and/or
 - Supervision
- ▶ Lives in Washington State
- ▶ Not receiving public respite elsewhere

Registered Agencies & Organizations

- ▶ In-home care
- ▶ Medical home care
- ▶ Adult day program
- ▶ Specialized community case aides
- ▶ Social skills programs
- ▶ Child care
- ▶ Camps
- ▶ Parks & recreation programs
- ▶ Others? (Caregiver choice)



RPAs register through a simple online application process that includes the application, their COI, and a signed Inter-Agency Agreement.

Respite Provider Agencies must:

- Conduct staff background clearances
- Carry their liability insurance
- Meet staff training requirements

Vouchers Do Not:

- Pay out to individuals
- Allow transportation
- Tell Respite Provider Agencies who to hire, what services to offer, or how much they can charge.

Priority Funding Streams

- 
- Children/Youth with Special Health Care Needs (CYSHCN) - Maternal Child Health Funds through Department of Health
 - Traumatic Brain Injury
 - Tribal Respite Grant
 - Individuals with intellectual/developmental disabilities ("No Paid Services")
 - Rural Communities
Application Date Order



Department of Health, Children with Special Health Care Needs

- ▶ Maternal Child Health Funds
- ▶ 10 applications per fiscal year
- ▶ Referred by Local Health Jurisdictions
- ▶ \$1,000 per child versus per household
- ▶ Medicaid eligibility
- ▶ Creates partnerships/entry path for families to also use a respite camp until the child ages out.
- ▶ A “broker” system that could be replicated

Tribal Respite Grant

- Companion Lifespan Respite Grant to work with 8 Tribes
- Respite for kinship caregivers
- Determine with Tribes how they define respite
- Support their respite projects
- Learn from the Tribes how best to honor their caregivers; e.g., identifying community caregivers as important to include in respite.
- Provide education and training regarding their areas of interest; e.g., special needs care, ACEs, etc.
- Respite projects included regalia making, attendance for children at leadership camps, basketball camps, etc.



Traumatic Brain Injury

- ▶ The need for respite exists.
- ▶ Difficulty qualifying or being eligible for state assistance (DDA & Long-Term Support Services, Department of Health)
- ▶ Lifespan Respite is meant to be gap filler; focused on care receivers that are not receiving other benefits
- ▶ Design respite that might be non-traditional; e.g., care partner support versus caregiver or care receiver support
- ▶ New partnership: Brain Injury Alliance of Washington with a Lifespan Respite voucher referral emphasis

An Interview with Amy*



- Serves children under the age 7
- Reduce/prevent child abuse and neglect
- Overnight care, available 24/7
- Eastern WA, Spokane
- No government funding
- Serves over 4,000 children per year

* Reference "Liberating Structures" at the end of this slide show.





Paving the way to a sustainable future...

Traditional fundraising

Community partnerships



“Brokering” funding streams

Legislative revenue?

...a beacon of hope.



Questions?



Presenter Contact Information

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Family Caregiver Support Program Manager

Lifespan Respite Grant Director

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In case you are interested, following are extra slides to take with you:

WA State In-home Care Workforce

- 75-hour Training Requirements by statute - required to take the home care aide certification exam.
- Includes:
 - Orientation (2 hours introductory information orienting new workers to care setting and job)
 - Safety (3 hours on safety practices)
 - Basic (70 hours)
 - Core basic training - basic skills and information needed to provide hands on personal care;
 - Population specific basic training - tailored to a specific group of clients and their unique care needs due to their disease, condition, and/or stage of life.
 - Must occur within 120 days of hire.
 - Recent legislation provides some exception for family members

[75 Hour Training and Home Care Aide Certification PDF](#) and

[Google search for becoming a paid caregiver](#)

Liberating Structures

- Frequently used by Lifespan Respite WA for trainings, meetings, and summits.
- An alternative, interactive approach/design for how people work together instead of sitting in rows and watching/listening to a presenter.
- Engaging and innovative.
- For more information - [Liberating Structures Website](#)



[Link for the example used in this presentation, the interview with Amy](#)



What is a “Special Need”?

ADULT - a person 18 years of age or older who requires care or supervision to:

- Meet the person’s basic needs;
- Prevent physical self-injury or injury to others; or
- Avoid placement in an institutional facility.

[Lifespan Respite Act](#)

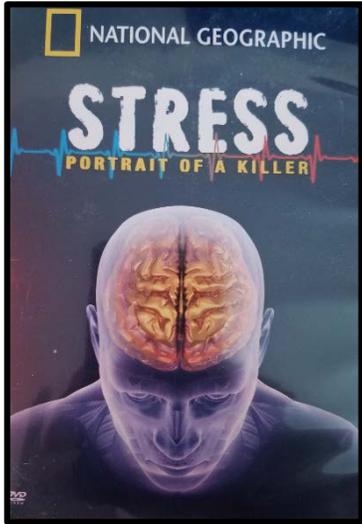


Special Need: CHILD

An individual less than 18 years of age who requires care or supervision beyond that generally required for children to:

- Meet the child's basic needs; or
- Prevent physical injury, self-injury, or injury to others.

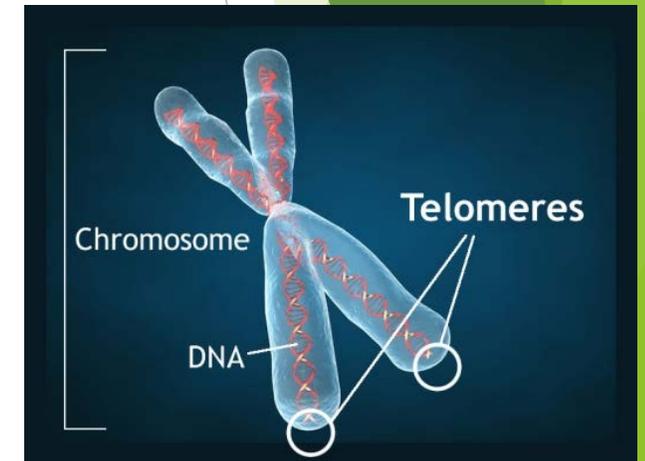
[Lifespan Respite Act](#)



National Geographic Society: A Documentary of Caregivers

- Stress of caregiving is linked to chromosomal damage
- Frayed telomeres* can recover through:
 - Engaging in shared humor about their situations
 - Connecting with other caregivers
 - Getting breaks from the burdens of caregiving

From the work of Dr. Robert Sapolsky, MacArthur Genius Award winner and professor at Stanford University



*Telomeres - caps at the end of each strand of DNA protecting chromosomes

Respite Options in Washington

- Family Caregiver Support Program
- Medicaid Alternative Care/Tailored Support for Older Adults
- Developmental Disabilities Administration
- Lifespan Respite Washington

Washington State's Long-Term Services and Supports: Aging and Long-Term Support Administration

Vision

Adults who are older or people with disabilities living in good health, independence, dignity, and control over decisions that affect their lives

Mission

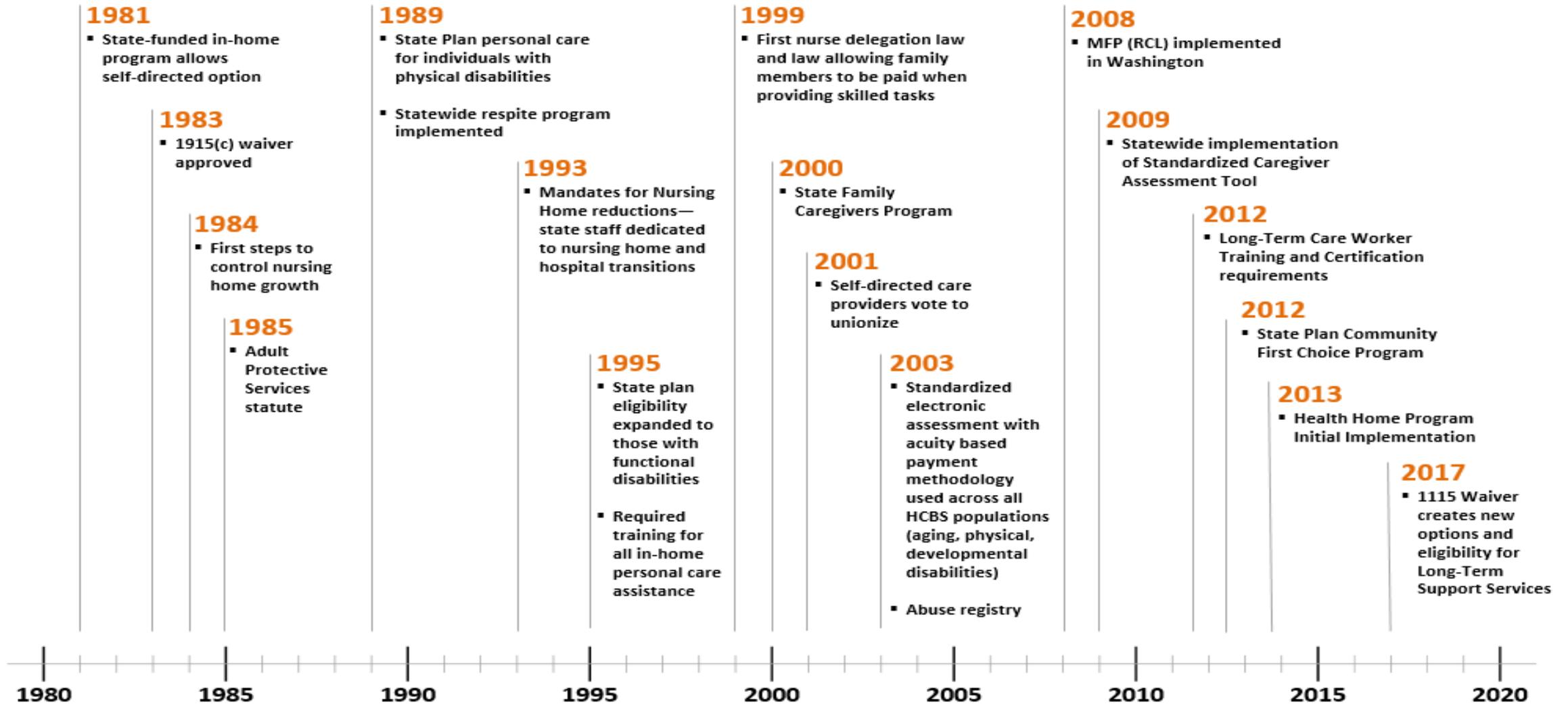
To Transform Lives by promoting choice, independence and safety through innovative services

In 2017, Washington State was ranked **first in the nation** in the Long-Term Services and Supports State Scorecard

AARP Foundation

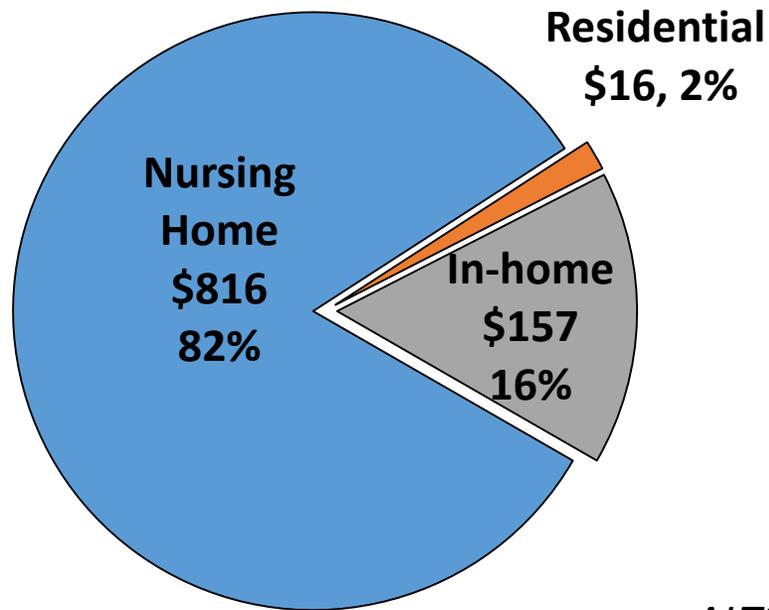


How did WA get here? LTSS Program Innovations

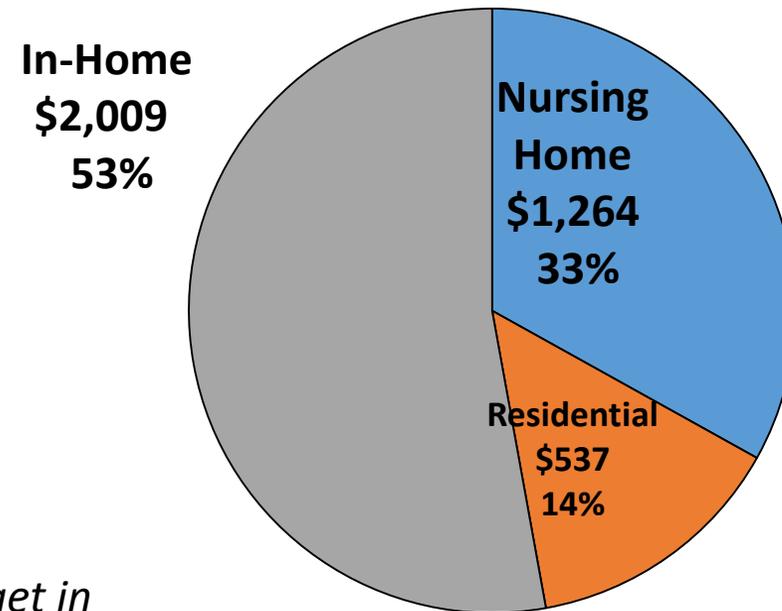


Funding for home and community-based care is now the majority of the state's investment in LTSS

1991-1993 Biennium

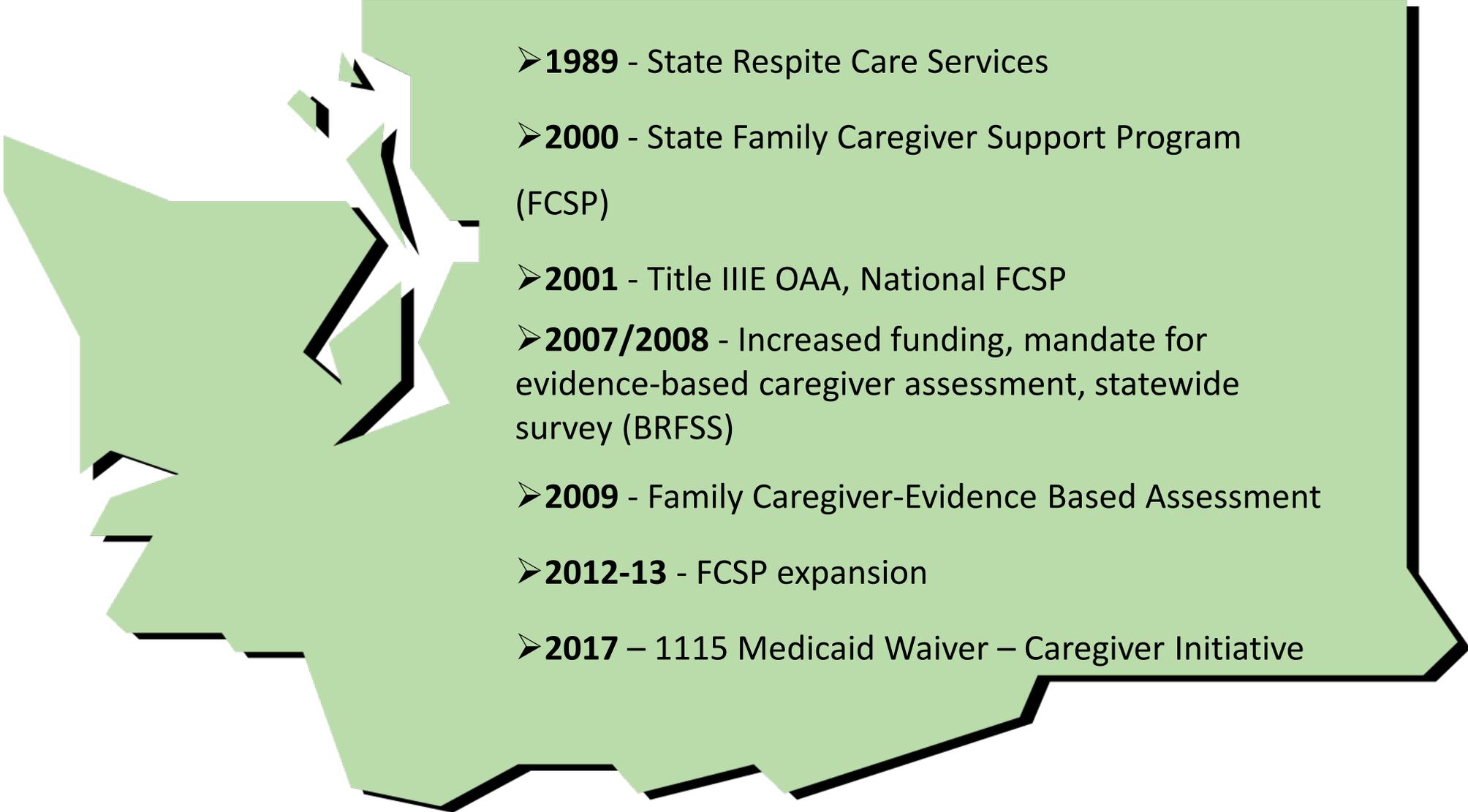


2015-2017 Biennium



ALISA budget in Millions of Dollars

Caregiver Programs in Washington

- 
- **1989** - State Respite Care Services
 - **2000** - State Family Caregiver Support Program (FCSP)
 - **2001** - Title III E OAA, National FCSP
 - **2007/2008** - Increased funding, mandate for evidence-based caregiver assessment, statewide survey (BRFSS)
 - **2009** - Family Caregiver-Evidence Based Assessment
 - **2012-13** - FCSP expansion
 - **2017** – 1115 Medicaid Waiver – Caregiver Initiative

Family Caregiver Support Program (FCSP)

- Washington's 13 Area Agencies on Aging
- OAA and state of Washington funded
- 1984 Began as project with 5 AAAs
- Caregiver and care recipient 18 years and older
- Social Security number not required
- No income eligibility (participation for respite on sliding scale)

<https://www.dshs.wa.gov/altsa/home-and-community-services/caregiver-resources>

FCSP Improves Outcomes for Family Caregivers

Majority of caregivers (84%) show significant improvements on key outcomes



Over 6-month period, caregivers who receive ongoing support show statistically significant improvements in:

- Stress burden
- Relationship burden
- Objective burden
- Depression
- Comfort with caregiving role

Spousal caregivers also show a decreased “intention to place”

The 1115 Demonstration Waiver Continuing LTSS Innovation

The LTSS of the Future must:

- Provide effective services for individuals before they spend down to Medicaid
- Provide effective supports to unpaid family caregivers
- Promote the right service at the right time and place
- Have the capacity to meet the needs of the population
- Strategically target LTSS Medicaid investments to slow the growth rate of public expenditures

Medicaid Alternative Care/Tailored Support for Older Adults MAC/TSOA

- 1115 Medicaid Transformation Demonstration
- 55 and older
- Financial eligibility higher than other state Medicaid programs
- Mirrors FCSP to provide services and supports to family caregivers

<https://www.hca.wa.gov/about-hca/healthier-washington/initiative-2-long-term-services-and-supports>

Questions?



For more information, please contact:

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Family Caregiver Support Program

Aging and Long-Term Care Administration

Lifespan Respite Grant Director

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