

# The Important Role of Family Caregivers in Washington State's Long-Term Services and Supports System

Bea Rector, Director

The Growing and Changing Nature of Family Caregiving

November 29, 2017



Transforming lives

# 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**

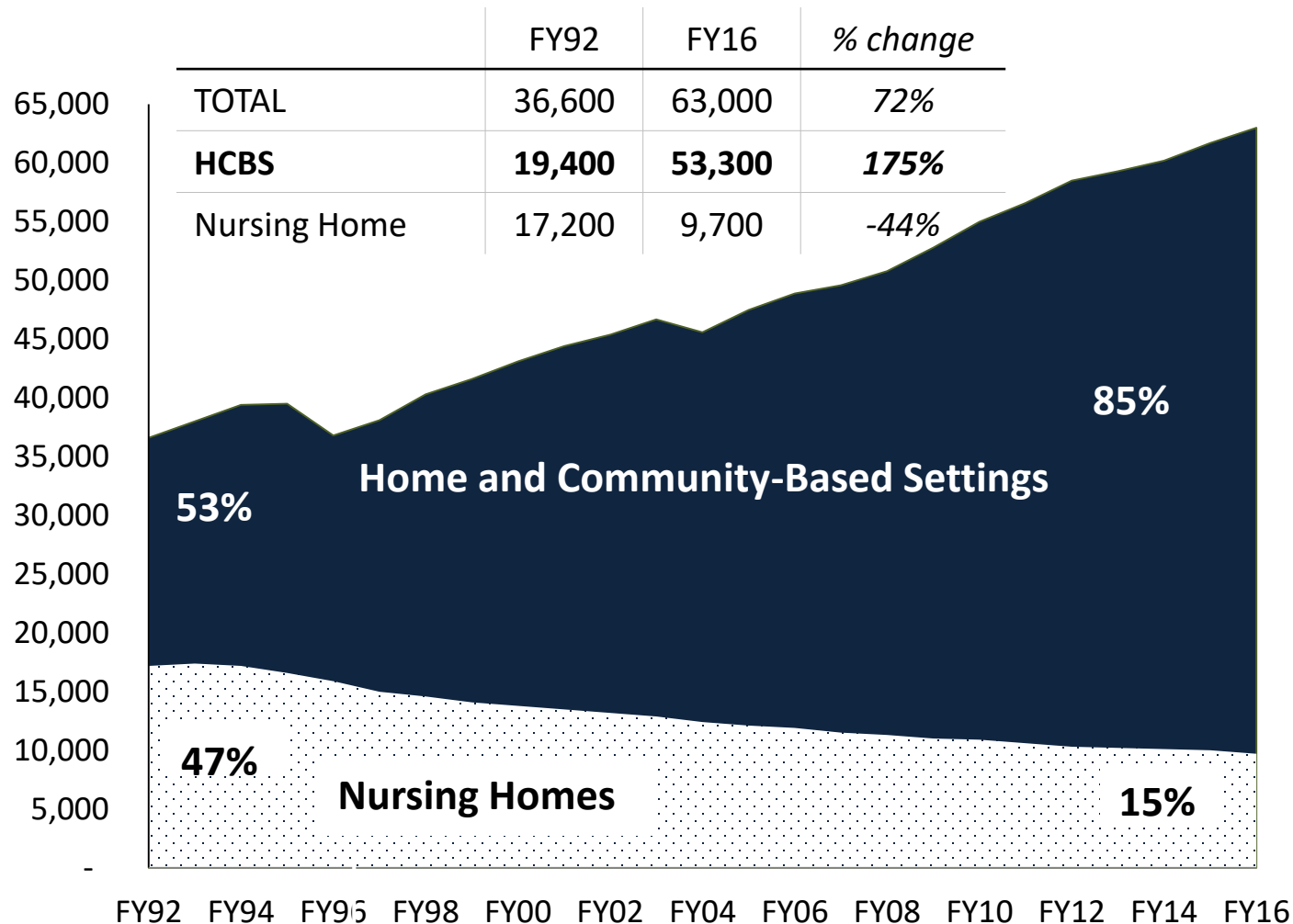


# Today's Presentation

## Long Term Services and Supports (LTSS)

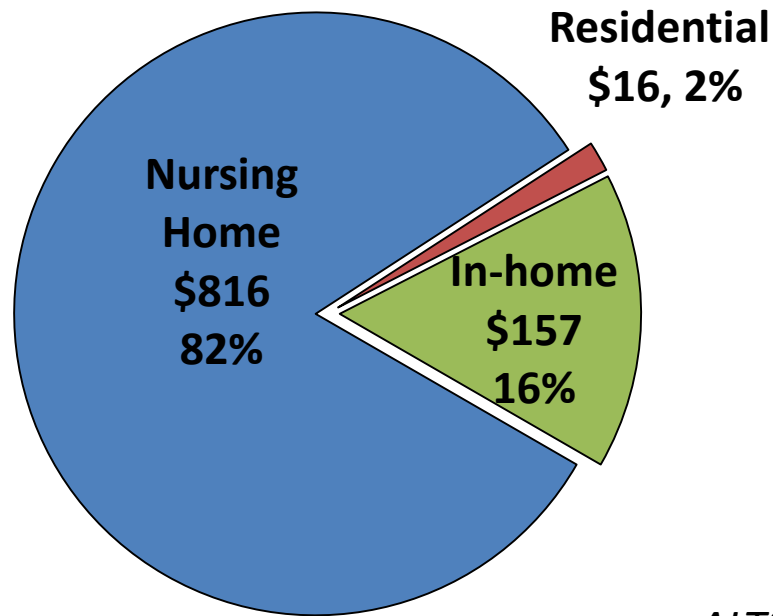
1. Medicaid LTSS - Successes and Challenges
2. Family caregivers in our LTSS System
  - Paid caregivers (qualified providers under Medicaid)
  - Unpaid caregivers
  - Medicaid Transformation Demonstration
3. Other Ways to Support Aging Populations and Caregivers

# Medicaid LTSS have been “rebalanced” to home and community-based services

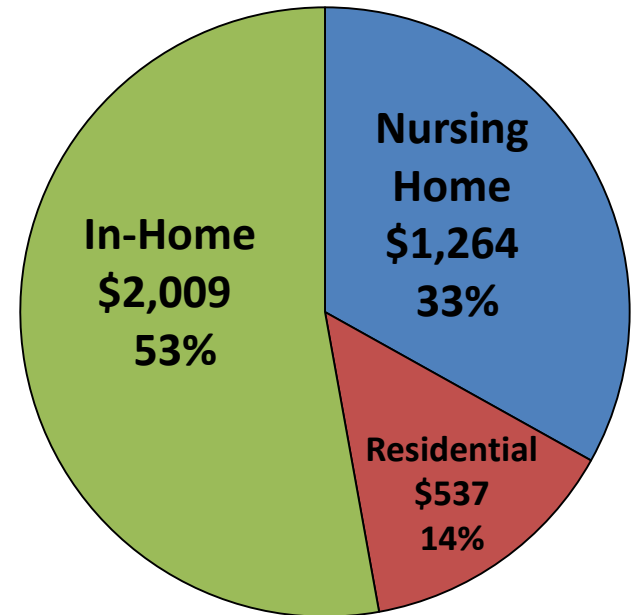


# Funding for home and community-based care is now the majority of the state's investment in LTSS

## 1991-1993 Biennium



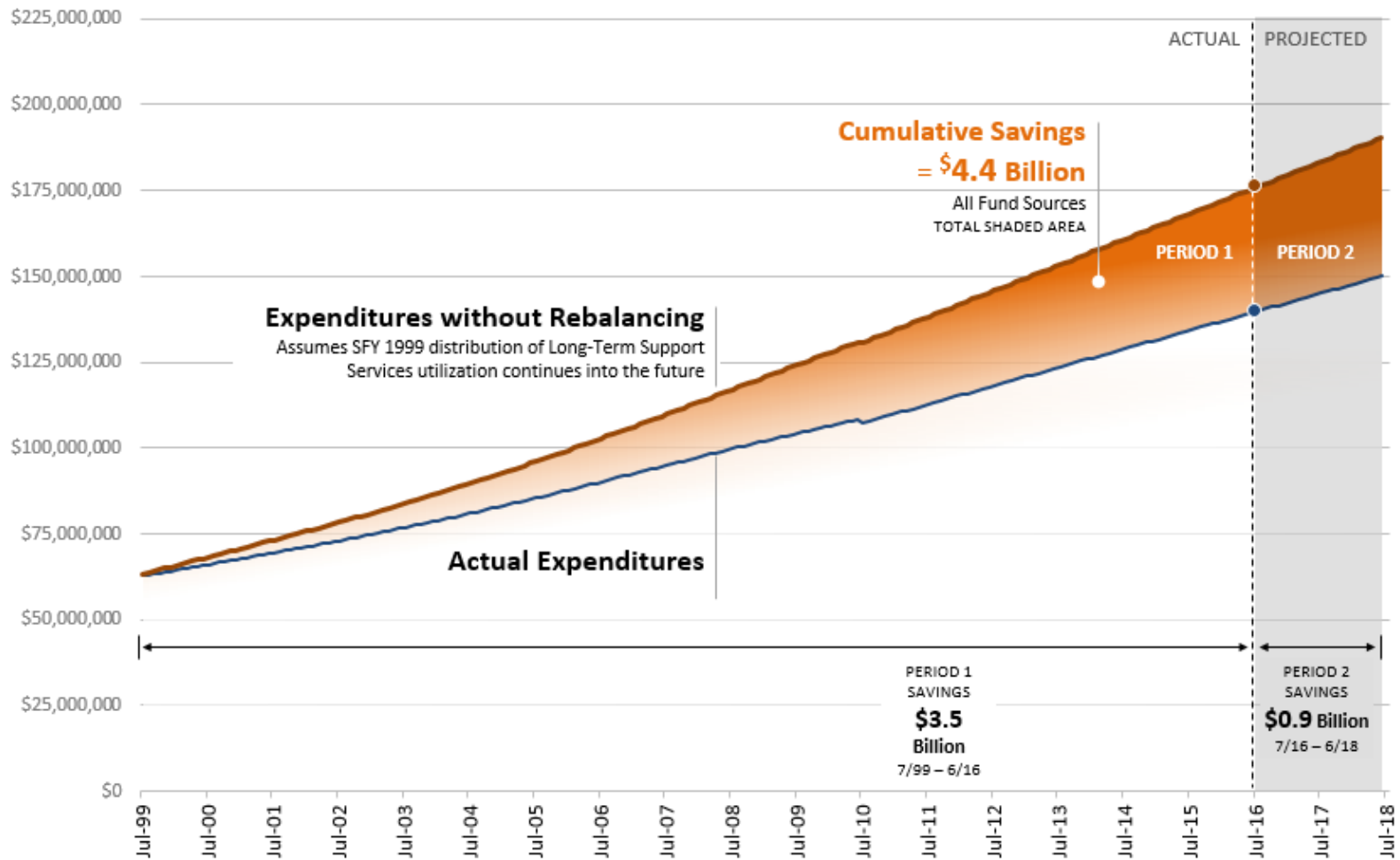
## 2015-2017 Biennium



*ALISA budget in  
Millions of Dollars*

# Savings to Washington's Medicaid LTSS due to Rebalancing

Monthly Service Expenditures • All Fund Sources • SFY 2000-2018



DATA SOURCE: RDA EMIS. For In-home Services, RDA EMIS caseload data are adjusted to Caseload Forecast Council caseload data from July 2003 to January 2005.

# No waitlist for Medicaid LTSS in Washington State, plus a variety of home and community-based options

## Medicaid State Plan

- "Entitlement"
- Mandatory Services
- Optional Services
- Statewide
- No cap & no targets
- About 83 % of budget

**Nursing Home**

**Medicaid  
Personal Care**

**Community  
First Choice**

## Medicaid Waiver

- Optional Services
- Not an "entitlement"
- Can be capped
- Target locations
- Target populations
- About 2 % of budget

**Community Options  
Program Entry System**

**New Freedom**

## Other

- State Only
- Federal Only
- About 4 % of budget

**Family Caregiver  
Support**

**Senior Citizens  
Services Act**

**Older Americans  
Act**

# How did WA get here? LTSS Program Innovations

**1981**

- State-funded in-home program allows self-directed option

**1983**

- 1915(c) waiver approved

**1984**

- First steps to control nursing home growth

**1985**

- Adult Protective Services statute

**1989**

- State Plan personal care for individuals with physical disabilities
- Statewide respite program implemented

**1993**

- Mandates for Nursing Home reductions—state staff dedicated to nursing home and hospital transitions

**1995**

- State plan eligibility expanded to those with functional disabilities
- Required training for all in-home personal care assistance

**1999**

- First nurse delegation law and law allowing family members to be paid when providing skilled tasks

**2000**

- State Family Caregivers Program

**2001**

- Self-directed care providers vote to unionize

**2003**

- Standardized electronic assessment with acuity based payment methodology used across all HCBS populations (aging, physical, developmental disabilities)
- Abuse registry

**2008**

- MFP (RCL) implemented in Washington

**2009**

- Statewide implementation of Standardized Caregiver Assessment Tool

**2012**

- Long-Term Care Worker Training and Certification requirements

**2012**

- State Plan Community First Choice Program

**2013**

- Health Home Program Initial Implementation

**2017**

- 1115 Waiver creates new options and eligibility for Long-Term Support Services



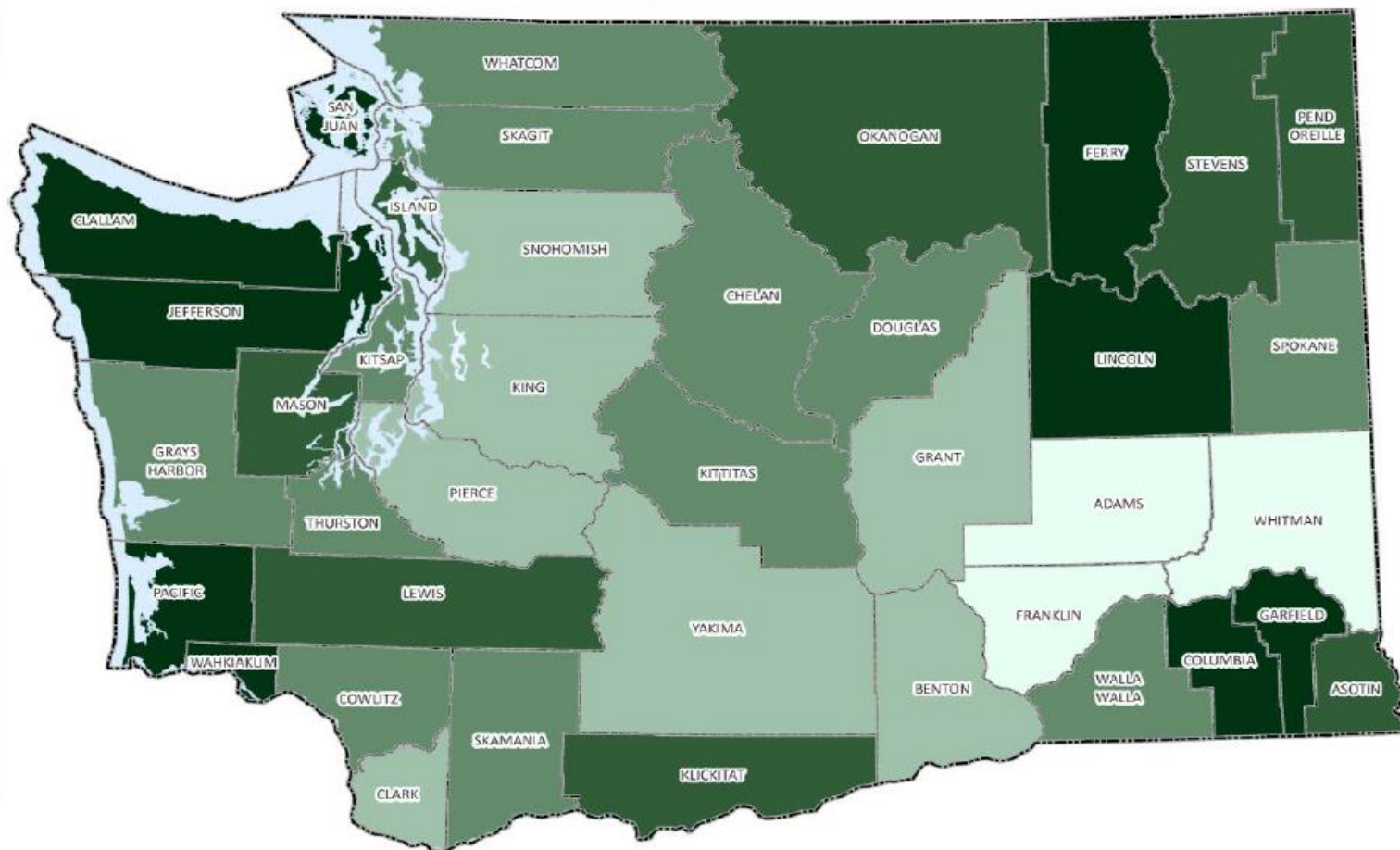
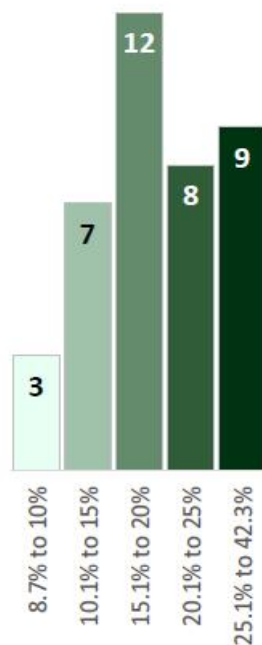


## Persons 65+ as a Percentage of the Total Population

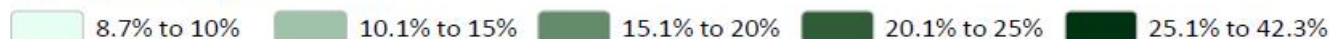
Estimates and Projections by County

# 2016

Number  
of counties



PERCENT OF SENIORS AGE 65+

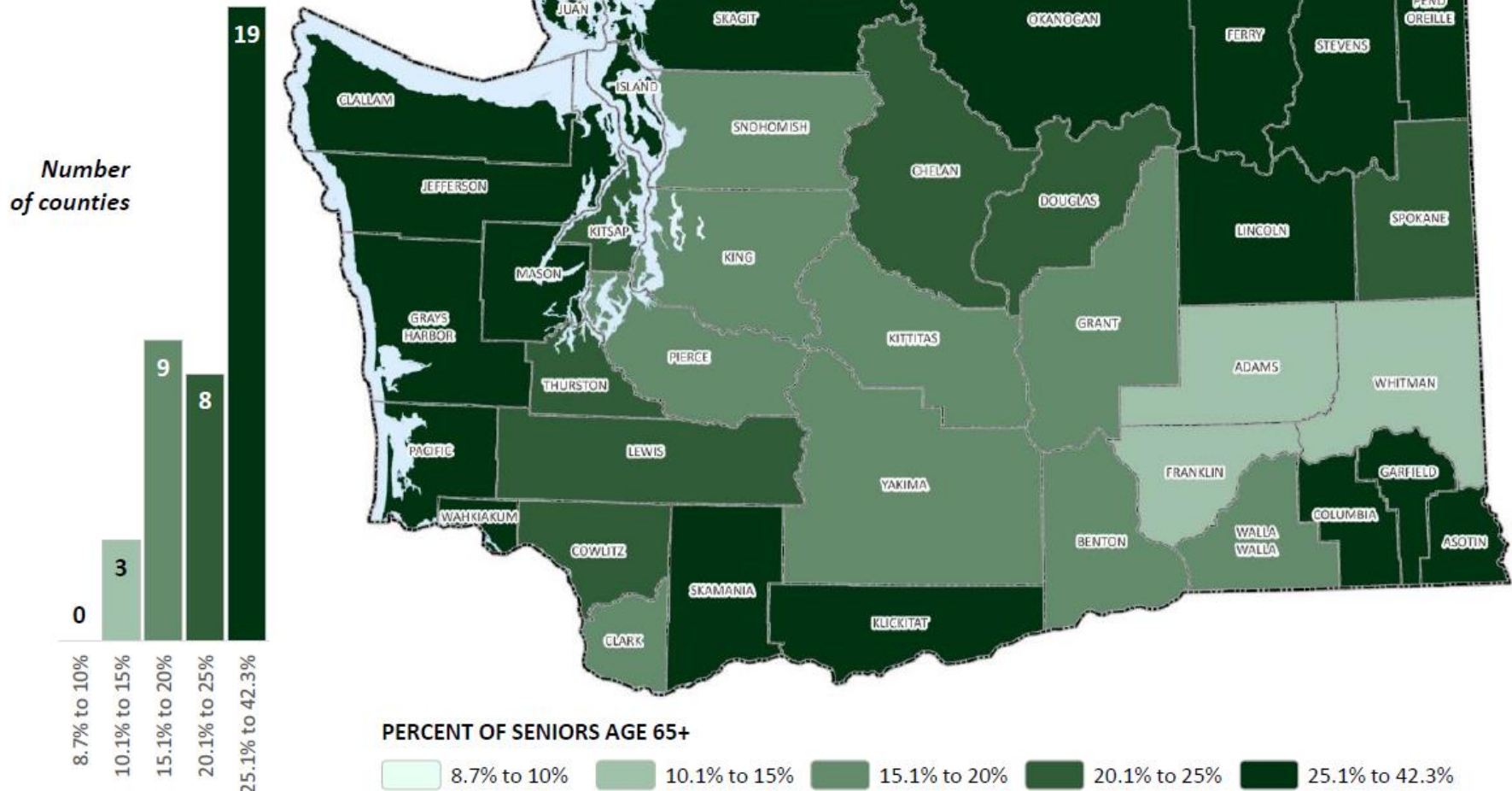


SOURCES: Washington State Office of Financial Management, 2012 County Growth Management Population Projections by Age and Sex: 2010-2040. Small Area Demographic Estimates (SADE) by Age, Sex, Race and Hispanic Origin: Counties, Version: 20161203\_R03\_VM.

## Persons 65+ as a Percentage of the Total Population

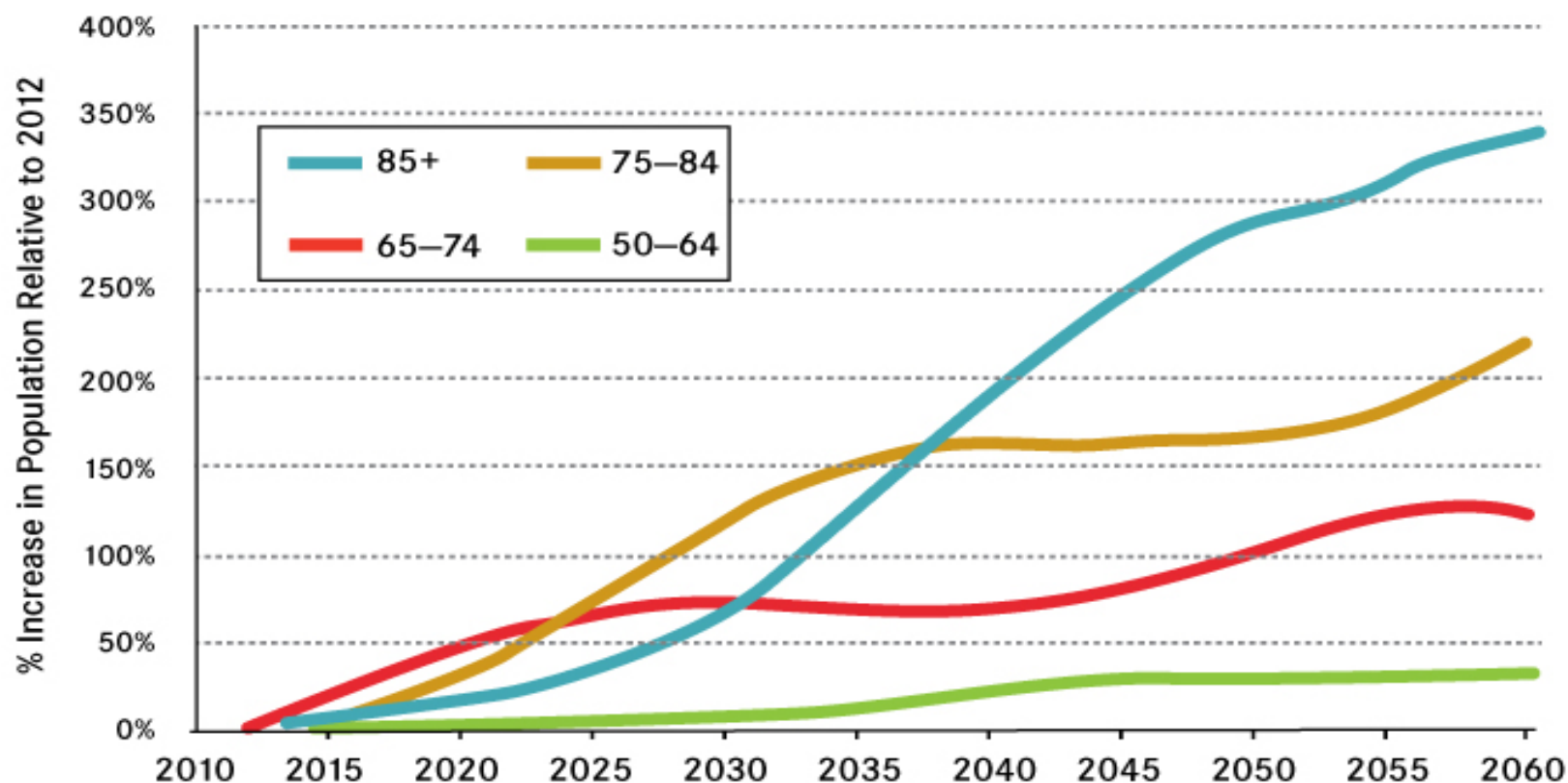
Estimates and Projections by County

# 2030



**SOURCES:** Washington State Office of Financial Management, 2012 County Growth Management Population Projections by Age and Sex: 2010-2040. Small Area Demographic Estimates (SADE) by Age, Sex, Race and Hispanic Origin: Counties, Version: 20161203\_R03\_VM.

## Projected Growth of Older Population in WA as Percent of 2012 Population







## A Day in the Life of a Caregiver

## Family Caregivers

Are key to LTSS in Washington State

### Medicaid

- Family members can become paid providers of LTSS for their loved ones

*Assistance is directed toward  
care recipient*

### Non-Medicaid

- Unpaid family caregivers who provide some or all care for their relatives

*Assistance directed toward  
caregiver*



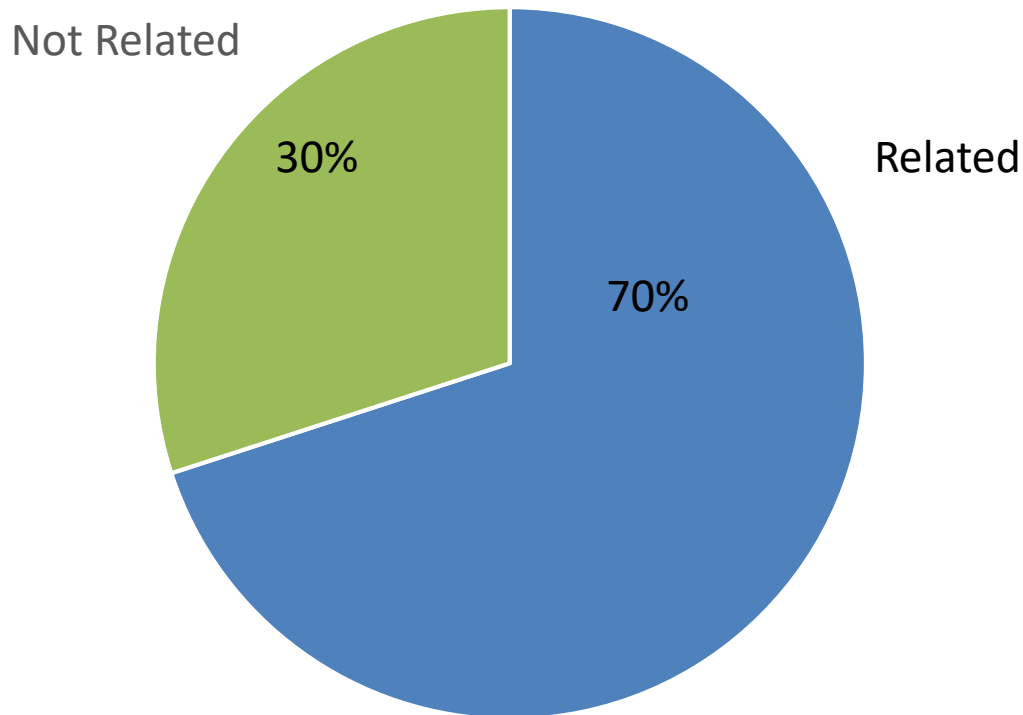
New Option: Medicaid Transformation Demonstration programs use *Medicaid to provide assistance for caregiver (and certain care recipients)*

## Family Caregivers:

### Largest Sector of Paid Medicaid LTSS Workforce

- Options to select family members to provide paid personal care services since 1981
  - Excludes legally responsible adults (spouses or parents of minor children)
- About 25,000 family members paid to provide care to Medicaid clients under state plan and waivers
- Required and optional training offered in multiple languages (training and certification in 11 languages with translation for others)
- Same pay and benefits as other workers
- Statute allows family to provide skilled care within paid hours

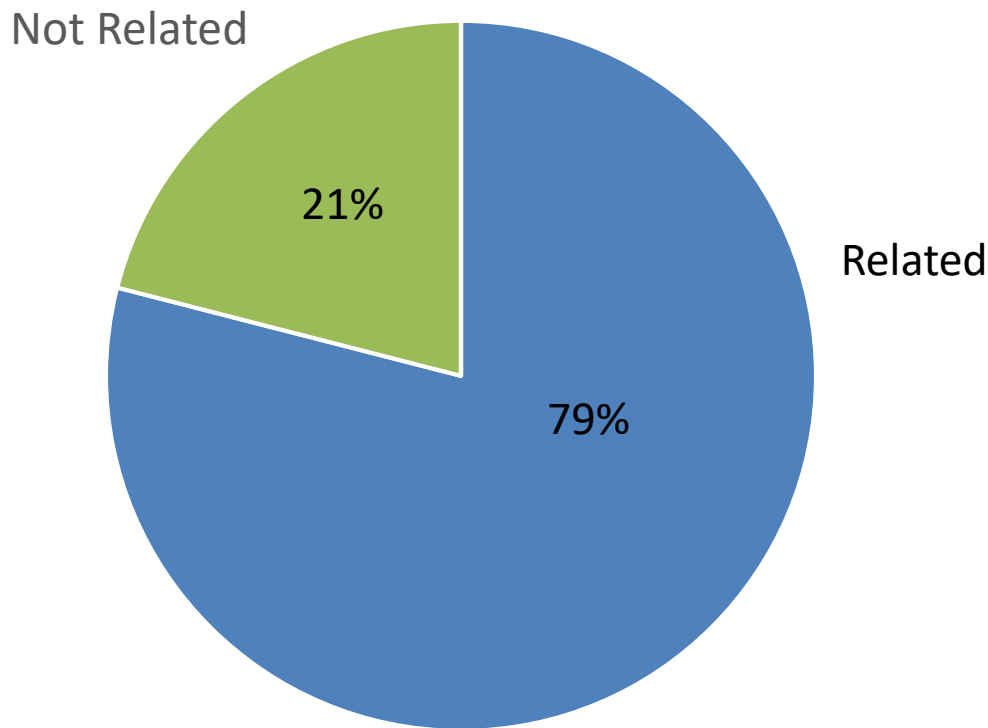
## Most paid providers of Medicaid in-home services are related to ALTSA clients



Relationship	%
Child	44
Parent	7
Daughter/Son-in-Law	6
Sibling	5
Grandchild	4
Niece/Nephew	2



## An even higher percentage of providers of Medicaid in-home services are related to clients of the Developmental Disabilities Administration



Relationship	%
Parent	56
Sibling	11
Grandparent	6
Aunt/Uncle	4
Cousin	1

# Unpaid Family Caregivers: A Washington State Priority

- Over 850,000 in Washington state
- Has an economic impact on families
- Economic value of \$10.6 billion a year (5 times what we spend in Medicaid LTSS)
- If 1/5 of unpaid caregivers gave up, it would double the cost of LTSS in Washington (which is already over 6% of state general funds)

**YOU CALL IT**

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**“bringing mom  
a few groceries.”**

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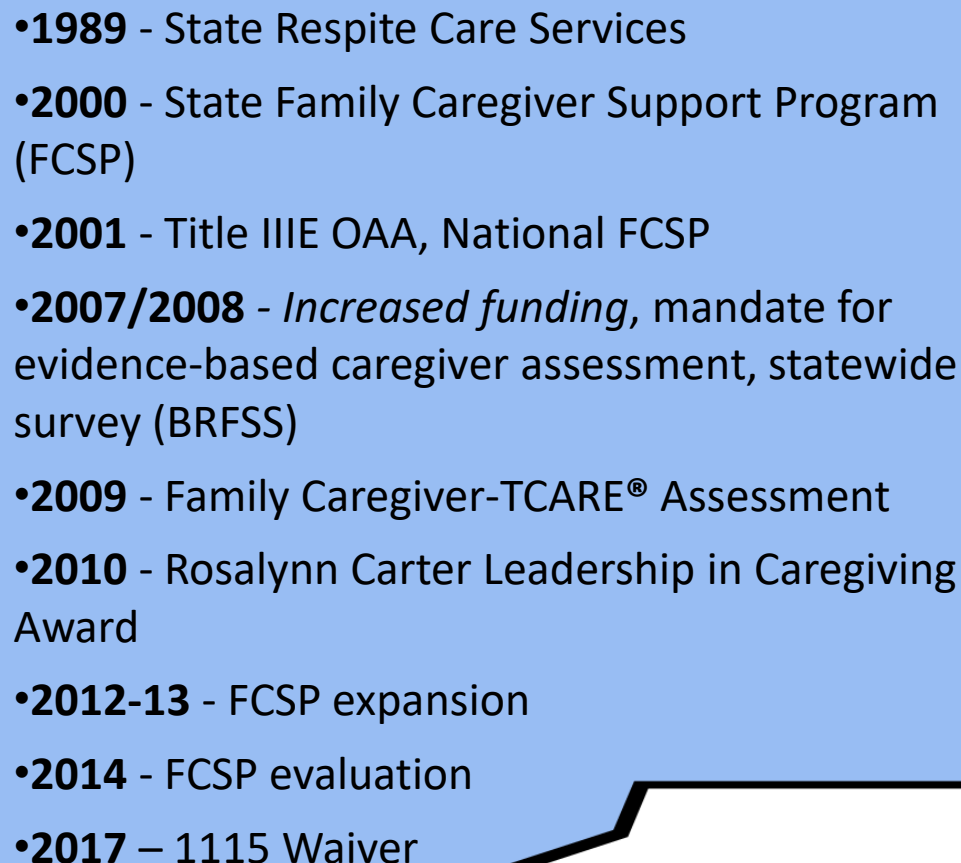
**WE CALL IT**

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**caregiving.**



## Washington's history of supporting unpaid family caregivers:

- 
- 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-TCARE® Assessment
  - 2010** - Rosalynn Carter Leadership in Caregiving Award
  - 2012-13** - FCSP expansion
  - 2014** - FCSP evaluation
  - 2017** – 1115 Waiver

# What have we learned about unpaid caregivers from our State Family Caregiver Support Program

## Unpaid family caregiver characteristics:

**61%** over age 60

**24%** ended their employment due to caregiving responsibilities

**59%** provided care for a minimum of two years

**29%** provided care for 5 or more years

**75%** spend at least 40 hours a week caregiving

**53%** are caring for individuals with Alzheimer's Disease or dementia

**82%** are coping with challenging behaviors of care receivers

## Caregiver-Centric Services

- Information & Options Counseling
- Use of Insurance, Private Finances, Community Resources
- Caregiver Training, Education & Support Groups
- Counseling & Consultation
- Respite, Housework & Errands
- Equipment & Supplies
- Health & wellness Referrals to cope with Depression & Medical Issues

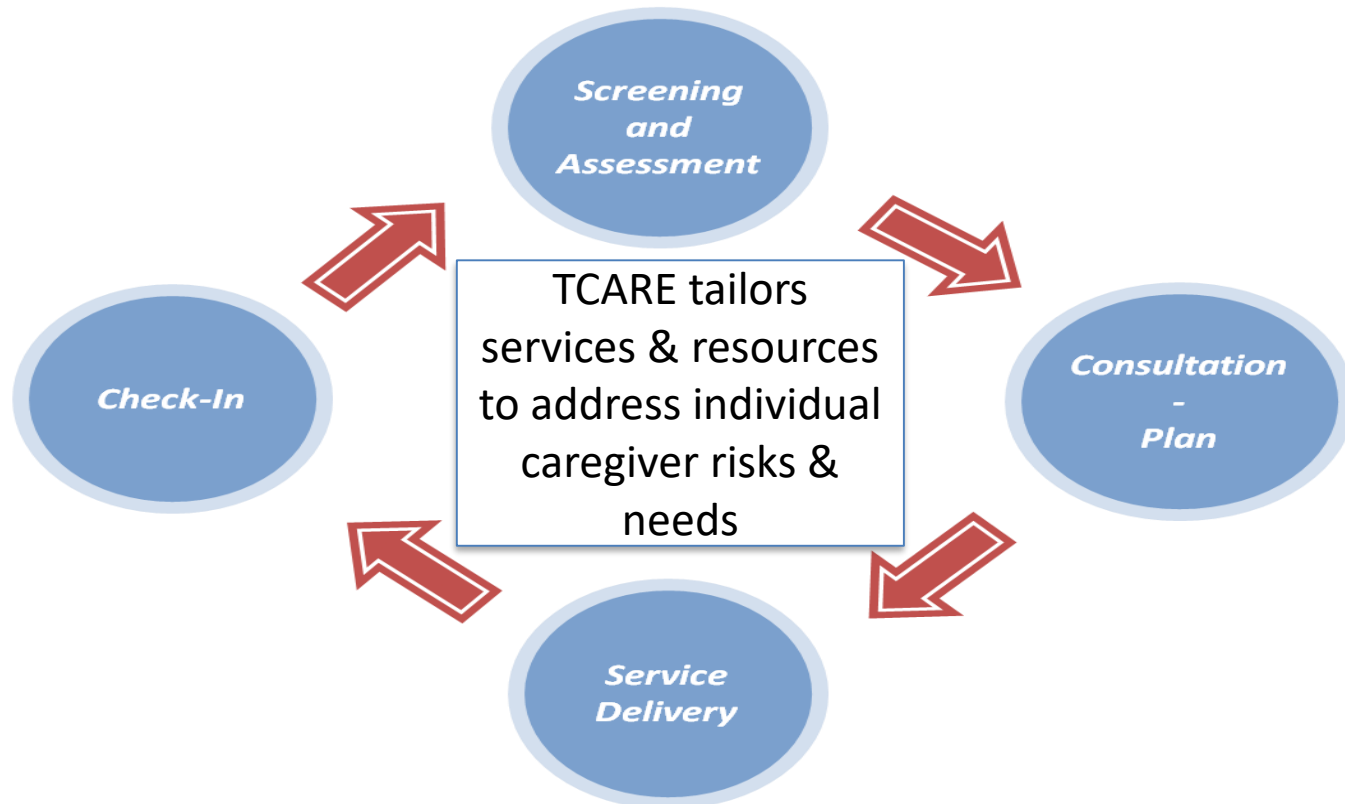
## Evidence-based Interventions

- Powerful Tools for Caregivers
- Reducing Disability in Alzheimer's Disease
- StarC
- Wisdom Warriors
- Fall Prevention



# Measuring Effectiveness of Interventions

In 2007, State Legislature mandated development of evidence-based caregiver assessment and referral tool (RCW 74.41).





# Improved Outcomes for Family Caregivers

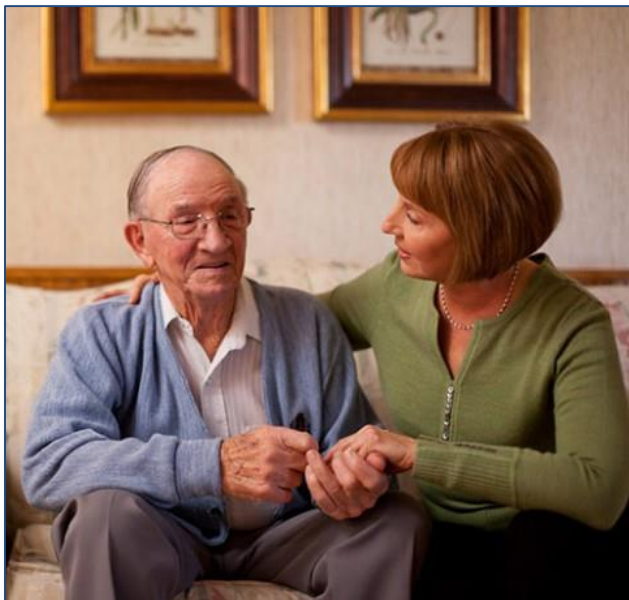
Over a 6-month period, caregivers who receive ongoing support show statistically significant improvements in:

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

Spousal caregivers also show a decreased “intention to place”

**84%**  
of caregivers show a  
significant  
improvements on  
key outcomes

# Attention to Caregivers Makes a Difference



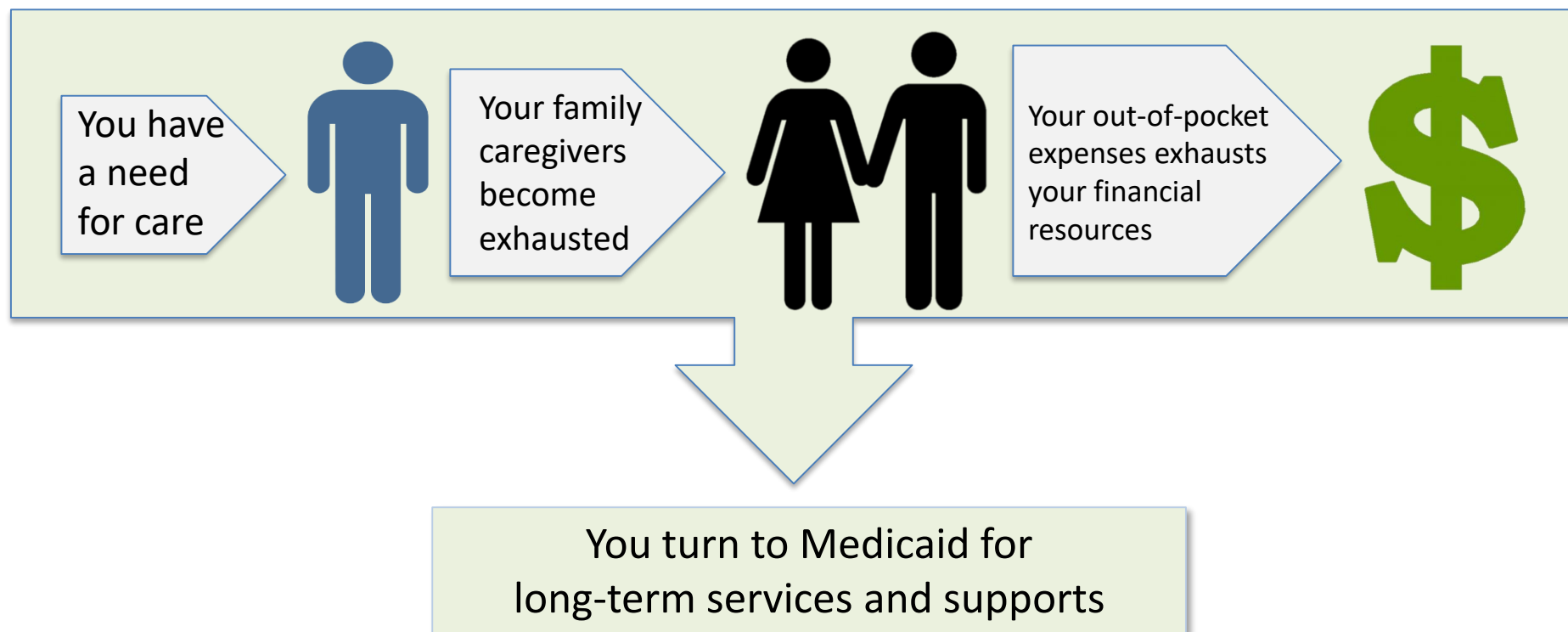
*"I was amazed in the first interview that a lot of the questions were **about me** and how I was doing...I wasn't expecting that."*

*"It was so helpful to have someone say 'you need to take care of **yourself** and here are services you can use'."*

**4 out of 5**

Caregivers reported that the **FCSP** helped them understand the importance of taking care of themselves.

# The path to Medicaid LTSS is common & predictable

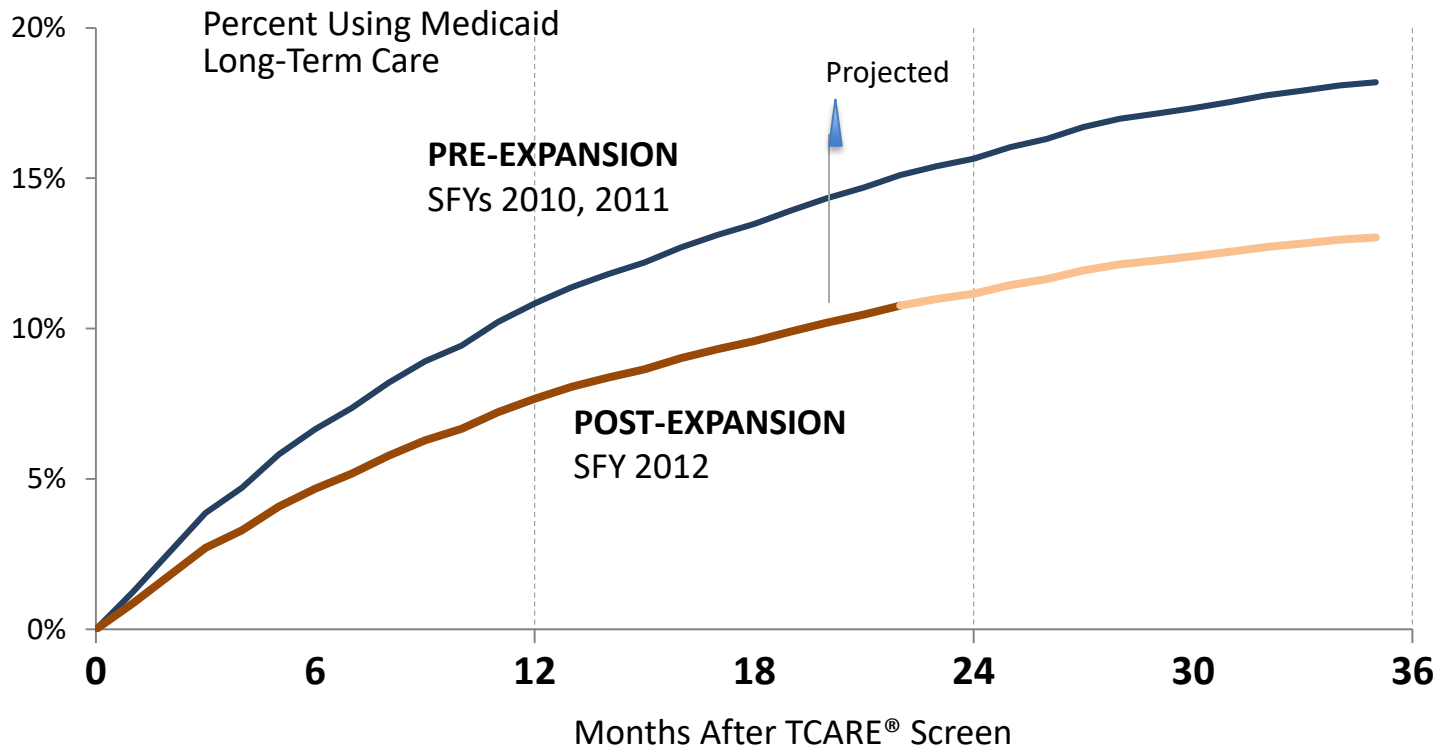


**Average Senior Retirement Savings = \$148,000**  
**Average Life Cost of LTSS = \$260,000**

We know that past expansions of family caregiver supports delayed use of traditional Medicaid.

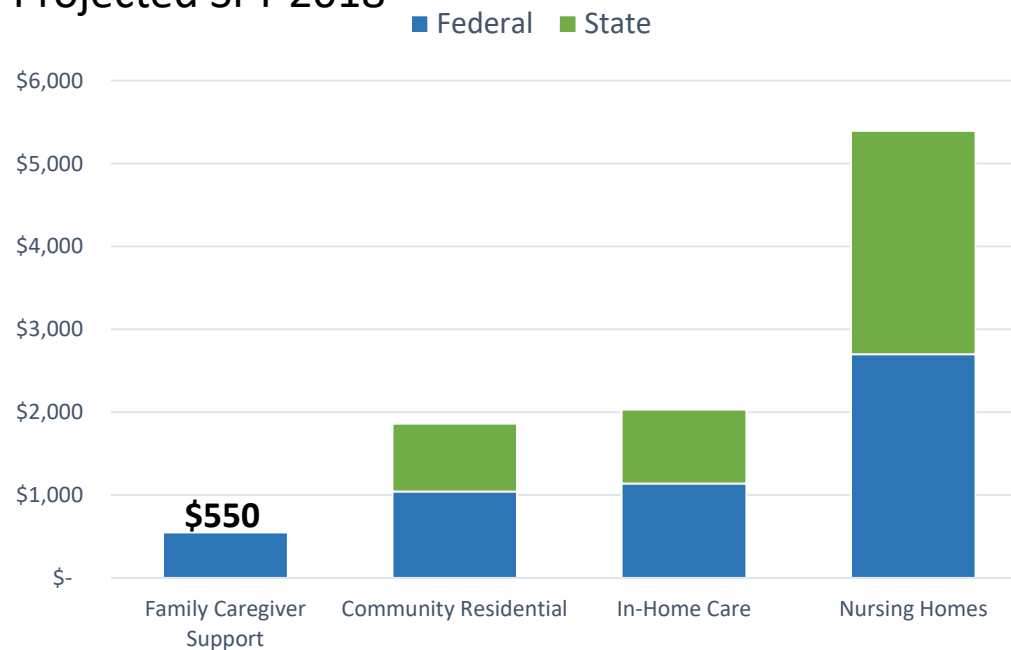
***Time from TCARE® Screen until First Use of Medicaid Long-Term Care***

*Pre- and Post-Expansion, Controlling for Baseline Differences*



Family Caregiver Support Services are a low cost option compared to traditional Medicaid LTSS *that until the Medicaid Transformation Demonstration had not received matching federal funds.*

Monthly Per Capita Costs – Medicaid LTSS  
Projected SFY 2018



# The Medicaid Transformation Demonstration

Innovative Demonstration Waiver approved by federal government to test and demonstrate whether providing certain services and supports as a choice for Medicaid clients will result in more person-centered, cost-effective methods of addressing needs for LTSS.



## Goals:

- Provide the right service at the right time
- Expand person-centered choices
- Support unpaid family caregivers and individuals at risk of institutionalization
- Delay or avoid the need for more intensive Medicaid funded LTSS

## LTSS Benefits in 1115 Waiver

- **Caregiver Assistance Services:** Services that take the place of those typically performed by unpaid caregiver
- **Training and Education:** Assist caregivers with gaining skills and knowledge to care for recipient
- **Specialized Medical Equipment & Supplies:** Goods and supplies needed by the care receiver
- **Health maintenance & therapies:** Clinical or therapeutic services for caregivers to remain in role or care receiver to remain at home
- **Personal Assistance Services:** Supports involving the labor of another person to help recipient (TSOA only)

## A New Choice Under Medicaid: MAC Support for Unpaid Caregivers

- Provide support for unpaid family caregivers who support individuals eligible for Medicaid but not currently accessing Medicaid-funded LTSS
- Provide necessary supports to unpaid caregivers to enable them to continue to provide high-quality care and focus on their own health and well-being

Age Requirements	Medicaid Requirements	Other Requirements	Benefit Level
The care receiver must be 55+ and the caregiver must be 18+ in age.	Requires the care receiver to currently be on Apple Health (Medicaid).	The care receiver must need help with some activities of daily living, like bathing, walking, medications, transfers, etc.	Depending on your situation, you could receive up to \$550 each month in services and supports.



## Delay Impoverishment: Tailored Supports for Older Adults

- Provide a benefit package for individuals at risk of future Medicaid LTSS use
- Help individuals and their families avoid or delay impoverishment and the future need for Medicaid-funded services while providing support to individuals and unpaid family caregivers

Age Requirements	Medicaid Requirements	Other Requirements	Benefit Level
The care receiver must be 55+ in age. Caregivers must be at least 18 years old.	Medicaid eligibility is not a requirement. As of 2017, financial eligibility includes gross monthly income less than \$2,205 and resources below \$53,100 for an individual or \$108,647 for a married couple.	The care receiver must need help with some activities of daily living, like bathing, walking, medications, transfers, etc.	Depending on your situation, you could receive up to \$550 each month in services and supports.

# Medicaid Transformation Demonstration: Presumptive Eligibility

Our two new programs under the Demonstration, MAC and TSOA, include Presumptive Eligibility, a truly innovative first for LTSS Medicaid.

## **What is Presumptive Eligibility?**

A process that allows us to gather preliminary information, based upon attestation, to decide that the care receiver appears to meet eligibility criteria and authorize services while full eligibility is being determined.

## Other Important Work to Support Caregivers



- CARE Act Passed in 2016
  - Designed to support caregivers and safe transitions from hospitals
- Paid Family Medical Leave Passed in 2017
  - Provides employees up to 12 weeks of protected leave in a 12 month period

# Washington is working to address Dementia: The Dementia Action Collaborative

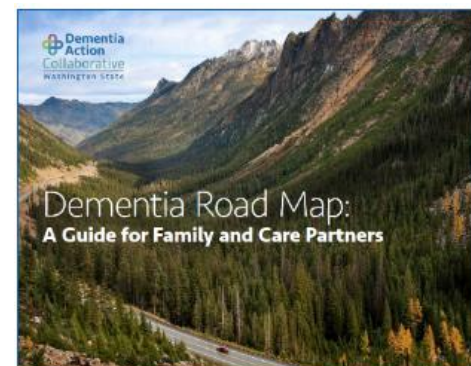
- Established in 2016, DAC is a group of public-private partners
- DAC creates resources for the public to raise awareness
- Currently, about 107,000 people in Washington state have Alzheimer's or other dementias
- By 2040, that number will grow to over 270,000



# The Dementia Road Map: A Guide for Family and Care Partners

## **What to expect and what you can do (action steps):**

- Wondering and Worried
- Mild Cognitive Impairment
- Early-Stage Dementia
- Mid-Stage Dementia
- Late-Stage Dementia



[Dementia Road Map: A Guide for Family and Care Partners](#)

# Strategies for States to Support Caregivers

## Overall

- Provide funding to assist family caregivers
- Use evidence-based models
- Collect data on family caregivers

## Medicaid Services

- Allow family to be paid in Medicaid programs
- Allow family to administer medications and provide skilled services even when paid
- Allow nurse delegation
- Provide care coordination and transition supports

## Other

- Family Medical Leave Act
- CARE Act
- Workplace Caregiver-Friendly Policies
- Action on Dementia



**For more information, please contact:**

Bea Rector, Director  
Home and Community Services  
(360)725-2272  
[RectoBM@dshs.wa.gov](mailto:RectoBM@dshs.wa.gov)

Websites:

General Information

<http://www.alsa.dshs.wa.gov/>

Family Caregiver Assessment & Resources

<https://www.dshs.wa.gov/alsa/stakeholders/caregiver-assessment-and-planning-tcare>