Washington State’s Support for Family Caregivers

We Transform Lives By:
*Promoting choice, independence and safety through innovative services.*

We Value:
*Pursuit of Excellence, Collaboration, Honesty, Respect, Open Communication, Diversity, Accountability, and Compassion.*

Bea Rector, Director, Aging and Long-Term Support Administration
Home and Community Services Division
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Topics for Today

• Background on Washington’s Long Term Services and Supports System
• Family Caregivers in Medicaid Programs
• Investing in Services for Unpaid Family Caregivers
• Lessons Learned from Recent Family Caregiver Support Program Expansion
• Strategies Used to Support Family Caregivers
Washington’s Long-Term Services and Supports (LTSS) rated 2\textsuperscript{nd} in the Nation

Indicators of system strength:

- Affordability and Access
- Choice of Setting and Provider
- Quality of Life & Quality of Care
- Support for Family Caregivers
- Effective Transitions

2014 LTSS Scorecard by AARP, The Commonwealth Fund, SCAN Foundation
Integrated Administrative Structure

Unlike many states, Home and Community Services, of Aging and Long-Term Support Administration, brings together under one administrative organization the Medicaid, Federal Older Americans Act, and state funded services and supports for adults with physical and cognitive disabilities and their caregivers.

Statewide network of:

- Access points for Medicaid program/financial eligibility determination and case management services
- Area Agencies on Aging providing in-home case management, Information and Assistance, and other community-based resources
- Statewide residential quality assurance programs
- Consolidated management functions
LTSS is almost a third of the DSHS budget

- **Long-Term Care**: 31%
- **Developmental Disabilities**: 17%
- **Mental Health**: 14%
- **Children’s Administration**: 10%
- **Economic Services**: 19%
- **Alcohol and Substance Abuse**: 3%
- **Juvenile Rehabilitation**: 2%
- **Administrations / Supporting**: 1%
- **Vocational Rehabilitation**: 1%
- **Payments to Other Agencies**: 1%
- **Special Commitment Center**: 1%
LTSS Development: 1980 - 1996

- 1983 - 1915(c) waiver began – One of the first in the nation
- 1989 - Legislature approves Medicaid Personal Care state plan as an entitlement to home & community services and created the statewide Respite Care Program
- 1995 - Legislation supported rebalancing of LTC system (ESSB 1908)
- 1996 - Nurse Delegation implemented
LTSS Development: 1995 - 2013

• 1999 – Laws passed that allow paid family and community providers to assist with skilled tasks
• 2000 - State Family Caregiver Support Program authorized and funded
• 2003 – Uniform Assessment (used for all disabilities and settings)
• 2013 Health Homes roll out
LTC Home and Community Services

LTC Clients Served in the Home and Community
1992-2013

Aging and Long-Term Support Administration
Rebalancing in Washington State

1991-1993 Biennium

- Nursing Home: $816, 82%
- In-Home: $157, 16%

2013–2015 Biennium

- Nursing Home: $1,212, 38%
- Residential: $433, 14%
- In-Home: $1,554, 48%

Dollars in Millions
Long-Term Care (LTC): most people get services in their own homes or in smaller community settings

FY 2012 Actual/Forecasted Data (Rounded)*

<table>
<thead>
<tr>
<th>Community Service Setting</th>
<th>ALTSA Clients</th>
<th>Total Funds Annual Cost (average)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-Home Care (Individual Provider &amp; home care agency)</td>
<td>35,000</td>
<td>$17,000</td>
</tr>
<tr>
<td>Boarding Homes/Assisted Living (Assisted Living, avg. 53 beds/home)</td>
<td>6,700</td>
<td>$14,000</td>
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<tr>
<td>Adult Family Home (up to 6 people per home)</td>
<td>5,400</td>
<td>$21,000</td>
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<tr>
<td>Total Community Settings</td>
<td>48,000</td>
<td>$17,500 (weighted average)</td>
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<tr>
<td>Family Caregiver Support Program (one time assistance – ongoing respite)</td>
<td>8,300</td>
<td>$1,500 (estimate range from $100- $5,500)</td>
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<tr>
<td>Institutions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing Homes</td>
<td>10,000</td>
<td>$57,000</td>
</tr>
</tbody>
</table>

Data is from ADSA forecasting (November 2012)
*Totals may not add due to rounding
** Per caps are driven by acuity of clients served and scope of services included in the setting
Projected Growth of Older Population in WA State as % of 2012 Population

The graph above illustrates the projected growth of older population in WA State as a percentage of the 2012 population. The x-axis represents the years from 2010 to 2060, while the y-axis shows the percentage increase in population relative to 2012. The graph is color-coded by age groups: 85+ (teal), 75-84 (yellow), 65-74 (red), and 50-64 (green).
Why Invest in Family Caregivers?
Support for Family Caregivers: Interrupting the Path to Medicaid

- Over 850,000 Washington State citizens are unpaid family caregivers and provide care equal to 5 times the Medicaid LTSS budget and allow family members to remain at home for as long as possible.

- The path to Medicaid is common and predictable:
  - **STEP ONE:** Someone has a need for care
  - **STEP TWO:** Family caregivers become exhausted
  - **STEP THREE:** Out of pocket spending exhausts resources
  - **STEP FOUR:** Medicaid

- We **can help** families delay the point at which they must turn to Medicaid

- They benefit, and the state budget benefits
Approaches for Interrupting the Path to Medicaid

Help families delay the point at which they must turn to Medicaid through funding of:

- Information & Options Counseling
- Use of Insurance, Private Finances, Community Resources
- Caregiver Screening & Assessment
- Family Caregiver Support
- Evidence-based interventions
Today more than ever, we need to support unpaid 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

A 25 year history of supporting unpaid family caregivers
Washington State’s Family Caregiver Support Program

Services Include:

- Specialized Caregiver Information
- Caregiver Screening and Needs Assessment
- Consultation and Care Planning
- Respite Care
- Counseling
- Training/Education
- Support Groups
- Supplies/Equipment
- Physical and Mental Health/Wellness Programs Referrals
What We Know About Family Caregivers Served in FCSP

FCSP 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 (another **32%** caring for individuals with memory/cognitive problems)
• **82%** are coping with challenging behaviors of care receivers

WA State TCARE® Data, SFY 2014
Family Caregivers are a Vulnerable Population

45% of FCSP caregivers report their own health status to be:
- Fair
- Poor, or
- Very Poor

50% scored high on depression scale

Statewide health data indicate that caregivers as compared to non-caregivers:
- Have more physical and other limitations
- Are less likely to see a doctor when they need to because of cost*

Research confirms clear relationship between untreated depression and impacted physical health.

*WA State 2007, 2011 Department of Health BRFSS Data
Does the Family Caregiver Support Program make a difference?

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

The use of Tailored Caregiver Assessment & Referral (TCARE®) offers a consistent, consultative model across the state, allowing caregivers to make informed choices and provides accurate data for decision-making.
TCARE® = Caregiver Assessment and Consultative Planning Process

TCARE® tailors services & resources to address individual caregiver risks and needs

Right service at Right Time
“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’.”

Caregivers reported that the FCSP helped them understand the importance of taking care of themselves.
Family Caregiver Support Program
Expansion 2012 and 2013

• The intent of this expansion was to avoid serving caregivers “too little, too late”.
• Caregivers served with new funding were to have a somewhat lower (but still high) level of caregiving stress/burden/depression.
  o Before program expansion, state funding was $6.3 million. In SFY 2012, program expanded by $3.4 million, to serve 1500 new caregivers with in-depth services (e.g. assessment/care plan, ongoing services – respite care, in-home consultation series, etc.).
  o In SFY 2013, program expanded by $1.5 million, to serve 750 new caregivers.
What did we learn from the Family Caregiver Support Program Expansion?
Majority of caregivers (84%) show significant improvements on key outcomes:

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

Spousal caregivers also show a decreased “intention to place”
Family Caregiver Support Program
Outcomes for both Caregivers and Care Receivers

When caregivers access support earlier in their caregiver journey, before they are experiencing the highest levels of stress and burden:

- There is a statistically significant delay in the use of Medicaid long term services and support (LTSS) for the care receiver
- The caregiver’s health and well-being is improved
- The likelihood of the caregiver needing Medicaid LTSS is reduced
Use of Medicaid Long-Term Care in Year after Screening: Pre-versus Post-Expansion Comparison

- Used Medicaid Long-Term Care services in 12 months following TCARE® screen?

**PRE-EXPANSION**
SFYs 2010, 2011
TOTAL = 3,347

- No
  - Nursing Home: 89%
  - Community Residential Services: 4.2%
  - In-Home Services Only: 2.5%
  - Other: 4.5%

- Yes
  - Nursing Home: 11%

**POST-EXPANSION**
SFY 2012
TOTAL = 3,266

- No
  - Nursing Home: 91%
  - Community Residential Services: 3.4%
  - In-Home Services Only: 1.9%
  - Other: 3.6%

- Yes
  - Nursing Home: 9%
Time Until Use of Medicaid Long-Term Care: Controlling for Baseline Differences

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

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

   - **Percent Using Medicaid Long-Term Care**

     - **PRE-EXPANSION**
       - SFYs 2010, 2011
       - Projected

     - **POST-EXPANSION**
       - SFY 2012
Strategies States Can Use to Support Caregivers

- Allow family to be paid in Medicaid programs
- Allow family to administer medications and provide skilled services even when paid
- Nurse Delegation
- Care Coordination and Transition Support
- Family Medical Leave Act
- Workplace Caregiver-Friendly Policies
- Surveillance of Family Caregivers (e.g., BRFSS)
- State funding for Family Caregiver Support Program
- Evidence Based Models
“...I was given the tools to successfully give my wife the best gift of all, to be able to take care of her at home until she died. This alone meant so much to us both. It also enabled me to get through her long illness as well as I did.”

-Participant in the Family Caregiver Support Program
Questions?

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