WA State Unpaid Family Caregiver Data Journey

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Supporting Family Caregivers
The Backbone of the Long-Term Care System
WA History of Unpaid Caregiver Support

- 1984—State Respite Pilot—3 AAAs
- 1989—Statewide Respite Care Services
- 2000—State Family Caregiver Support Program (FCSP)
- 2001—Title IIIIE OAA, National FCSP
- 2007/2008—Increased funding, mandate for evidence-based caregiver assessment,
- 2008—statewide survey (BRFSS)
- 2009—Family Caregiver-TCARE® Assessment
- 2012/13—State FCSP expansion
- 2017–1115 Medicaid Demonstration Waiver—Caregiver Initiative
Outcomes for Family Caregivers

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

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

Spousal caregivers also showed a decreased “intention to place.”

84% of caregivers show a significant improvements on key outcomes
Family Caregiver Support Program

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

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

- Nursing Home
- Community Residential Services
- In-Home Services Only

No 89%
Yes 11%

POST-EXPANSION
SFY 2012
TOTAL = 3,266

- Nursing Home
- Community Residential Services
- In-Home Services Only

No 91%
Yes 9%

[Source](https://www.dshs.wa.gov/ffa/rda/research-reports/expanding-eligibility-family-caregiver-support-program-sfy-2012)
Family Caregiver Support Outcomes

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

Source: Bridget Lavelle, PhD; David Mancuso, PhD; Alice Huber, PhD; Barbara E.M. Felver, MES, MPA; DSHS Research and Data Analysis, April 2014.
Expanding Supports: 1115 Waiver

Medicaid Alternative Care (MAC)
Designed to support unpaid caregivers in continuing to provide quality care.

Tailored Supports for Older Adults (TSOA)
New eligibility group to support individuals who need Long-Term Services and Supports and are at risk of spending down assets to impoverishment with or without unpaid caregivers.
“Program participation appears to help delay or avoid the use of more intensive traditional Medicaid LTSS”

When family caregivers access support early in their caregiver journey, before they experience the highest levels of stress and burden:

- **1115 Interim Evaluation** showed significant improvement in ED and hospital use of care receivers 6 months after caregivers received supports.
- The likelihood of the care receiver using Medicaid LTSS is reduced.
- The caregiver’s health and well-being is improved.
If the latest Caseload Forecast Council actual and forecast caseloads remain below the Budget Neutrality Line, then In-Home Personal Care caseloads are consistent with the MAC and TSOA programs achieving the savings necessary to be budget neutral from a total funds perspective.
Next Steps for WA

- Renewal of the 1115 Waiver with strong Interim Evaluation data to support
- Sharing data with health payers to find partnering opportunities with the Aging Network
- Washington’s LTC Trust Act: WA Cares

TCARE Inc. use of WA’s and other states’ data has led to exciting refinement of the EBP tool itself. The future is now for expanding reach of clinical staff with AI.
Questions?

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360-725-2527
“Care” for “Caregivers”

Evidence-based caregiver support program preventing caregiver burnout
Hours of Care ≠ Caregiver Burnout

92 Peer-reviewed published papers
Identity Discrepancy

“Am I her daughter or her caregiver?”

FAMILY MEMBER | CAREGIVER
TCARE® User Journey

1. TCARE® Screen
   Triage Tool

2. TCARE® Caregiver Evaluation

3. Algorithms
   Determine Goal - Strategy - Intervention

4. Tailored Care Plan

5. Information & Referral
   Local Community Resources

6. Weekly Engagement

7. 3 Month Follow Up
## Tailored Care Plan

### 1. Caregiver Status
- **Caregiver Phase:** Phase 2
- **Intention to Place:** No
- **Caregiver Type:** No Way Nasturtium

### 2. CG Emotional Needs
- **Relationship Burden:** HIGH
- **Objective Burden:** MED
- **Stress Burden:** HIGH
- **Uplifts:** LOW
- **Depression:** MED
- **Identity Discrepancy:** MED

### 3. Care Receiver Needs
- **ADL:** LOW
- **IADL:** LOW
- **Problem Behaviors:** HIGH
- **Memory:** No

### 4. Caregiver Obligations
- **Employment:** Work full-time
- **Personal Care Hours:** 0
- **Household Care Hours:** 0
- **Other Assistance Hours:** 0
- **Total Dependents:** 2
Over 168+ categories of SDOH services...

Health Goal

D. Reduce generalized stress
- (15) Medical or Behavioral Health Related Services

E. Improve overall health
- (18) Medical or Behavioral Health Related Services

Goal 2: Embrace Caregiver Identity

A. Change personal rules for care
- (21) Counseling or (4.2) QIS Education psycho-social
- (4.1) Education for caregiver to obtain information about services and assist with planning for the future
- (4.2) Education to build caregiving skills (e.g., direct care and communication)
- (5) Skills for responding to mood and behavior changes

Amount/Frequency
<table>
<thead>
<tr>
<th>PRIMARY CARE CLINIC</th>
<th>Amount Frequency</th>
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<td>20 UNION ST N MDRA</td>
<td>1x/Week</td>
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B. Reduce or minimize work load
- (11) Adult Day Services (Experience time away from care responsibilities)
- (22) Assistive Technology (Promote safety and functional abilities of care receiver)
- (4.1) Education for caregiver to obtain information about services and assist with planning for the future
- (4.2) Education to build caregiving skills (e.g., direct care and communication)
- (5) Education for care recovery (facilitate self-care and/or reduce need for assistance)
- (8) Financial and/or Legal Services and Protection (Obtain assistance or counsel)
- (12) In-home Supports and Services (Reduce responsibility or workload)
Self-Directed caregivers
Direct Care caregivers
Foster Care

- MILITARY
- OLDER ADULTS /DEMENTIA
- DEVELOPMENTALLY DISABLED (IDD)
Predictive, data dashboards
Predictive Data Models

NURSING FACILITY

Probability of Service Use

- Service Used
- No Service

Low prob. observations

High prob. observations
EVIDENCE-BASED | CMS-APPROVED | HHS-ACCREDITED
AGING-IN-PLACE SOLUTION

tailoredcare.com

1st Place Award
INSURTECH
INNOVATION

SOCIETY OF ACTUARIES

1st Place Winner
AGING-IN-PLACE
INNOVATION

Kaiser Permanente

Top 10 HealthTech
Innovators Award

Accenture

Leadership in Caregiving
Award

ADVANCING STATES

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Maine Caregiver Programs: 
Current Data Status and Future Directions

Maine Department of Health and Human Services
Office of Aging and Disability Services
Federally Funded Programs

• National Family Caregiver Support Program (OAA, Title III-E)
• Section 19: HCBS Older Adults & Adults w/ Disabilities (MaineCare)
  – Respite is a covered service
• Section 26: Day Health Services (MaineCare)

State Funded Programs

• Section 61: Adult Day Services
• Section 63: Home Based Care (HBC)
  – Respite is a covered service, cannot exceed annual cap
• Section 68: Respite Care Services for Adults with ADRD
Statewide Needs Assessment

- >26% reported finding information about available services and programs either very or somewhat difficult
- Those who said they had not received all of the help they needed, 40% said they did not know whom to ask for help
- Caregivers who said they were not getting the help they needed, 26% said they did not know whom to ask or where to get the information
- Expressed the need to get information from a trusted or reliable source

ADRC Calls

Unduplicated Calls from Caregivers by Federal Fiscal Year

Data pulled from WellSky Aging & Disability on 11/18/2021

Maine Department of Health and Human Services
AAA Respite Care Program

Number of Caregivers & Respite Hours Served by Federal Fiscal Year

- Unduplicated Caregivers
- Hours of Respite

Data pulled from WellSky Aging & Disability on 11/18/2021
Current Data Gaps

- Limited to units, persons, and expenditures
- No population health outcomes being measured
- Only tracking Alzheimer’s Disease diagnosis
- Assessment data is inconsistent across AAAs and programs
- Only tracking race and ethnicity, no data on sexual orientation and gender identity
- Lack of ability to track clients across their life course
Future Family Caregiver Initiatives

• TCARE Assessment and Management Protocol (MFP Capacity Building)
  – Starting with AAAs, but looking to expand into other populations
  – Stakeholder group developing implementation plan

• Family Caregiver Grants Pilot (ARP)
  – $2,000 grants to eligible family caregiver impacted by the pandemic
  – $5.1 million allocated to the project ($4.5 for direct grants)
  – Stakeholder group guiding design, implementation, and evaluation

Related Initiative

• Community Information Exchange (CIE)
  – Connecting various databases to better track SDOH and across systems
What data do we want to collect and analyze?

• TCARE
  – Better assessment data on caregiver burden and stress over time
  – Correlations between caregiver demographics and outcomes
  – Delayed entry into long-term care and potential savings
  – More accurate dementia diagnosis of care receivers (e.g., frontal temporal, vascular, Parkinson’s, Alzheimer's, etc.)

• Family Caregiver Grants Pilot
  – How are we going to measure “negatively impacted and/or suffered economic harm because of COVID-19”?
  – For working caregivers, did this assistance continue participation in the workforce?
  – Did the assistance delay entry into long-term care?
  – What other benefits, services, programs, etc. did the family caregiver access through this project?
Questions?

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