

Family Caregiver Support Program Update

Joint Legislative Executive Committee on Aging and Disability

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May 19, 2014

April 2014 | RDA Report 8.31
Olympia, Washington



Expanding Eligibility for the Family Caregiver Support Program in SFY 2012

Updated Findings

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In collaboration with Susan Engels, Office Chief, State Unit on Aging, Aging and Long-Term Support Administration, Home and Community Services Division.

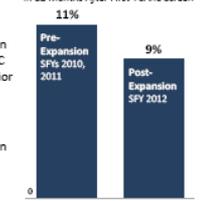
WASHINGTON STATE'S FAMILY CAREGIVER SUPPORT PROGRAM (FCSP) serves Washingtonians who provide uncompensated care for a parent, spouse, or another adult with medical issues, mobility limitations, or decreased cognitive functioning. In a 2007 statewide survey, the Washington State Department of Health found that many family caregivers feel time-constrained and have high levels of stress.¹ Designed to mitigate these burdens, FCSP services include information and outreach, screening and assessment, respite care, support groups, and resources to assist with mobility limitations and other needs. One goal of providing FCSP services is to delay or make unnecessary the placement of care receivers in long-term care facilities.²

The 2011 Legislature increased the state funding for FCSP in State Fiscal Year (SFY) 2012 by \$3.45 million dollars. The expansion allowed FCSP to broaden its reach to family caregivers with a wider range of caregiver burdens, as identified by an evidence-based screening tool, the Tailored Caregiver Assessment and Referral System (TCARE®).³ A legislatively mandated evaluation of the expansion, completed by the Washington State Institute for Public Policy (WSIPP) in November 2012, demonstrated promising findings. Using data from the short follow-up period available at that time, WSIPP found that the expansion was associated with delayed use of Medicaid long-term care services (LTC).⁴ This report revisits the question of how the FCSP expansion affected the use of Medicaid LTC, now that care receivers' outcomes have been observed for a longer period of time.

Key Findings

- Due to the FCSP expansion, caregivers screened in SFY 2012 were more likely to receive a full assessment and a broader range of support services than those screened in prior years.
- Care receivers whose caregivers were screened post-expansion were about twenty percent less likely to enroll in Medicaid LTC services in the 12 months following screening compared to prior years (9 vs. 11 percent), despite the fact that more post-expansion care receivers were already enrolled in Medicaid medical coverage at the time of screening.
- Care receivers whose caregivers were screened post-expansion were slower to transition to Medicaid LTC, controlling for differences in baseline characteristics; the FCSP expansion is likely a contributing factor to this positive outcome.

Use of Medicaid LTC Services
In 12 Months After First TCARE Screen



Department of Social and Health Services | Research and Data Analysis Division



DSHS Research and Data Analysis Division, April 2014: <http://publications.rda.dshs.wa.gov/1502>



Support for Family Caregivers: Interrupting the path to Medicaid is Critical

Each year the 850,000 informal caregivers in Washington provide **\$10.6 billion** of unpaid assistance to individuals needing assistance to stay in their homes

Contrast this with the **\$1.5 billion** spent on Medicaid Long Term Services and Supports (LTSS) each year which covers:

- Nursing homes
- Personal care and supportive services in licensed residential settings
- Personal care in the client's own home

Without these unpaid caregivers the amount needed for Medicaid LTSS would be much higher

*AARP Public Policy Institute, Valuing the Invaluable, 2011 Update



Family Caregiver Support Program Expanded in FY 2012

- **Family Caregiver Support Program**

- Provides supportive services for unpaid family caregivers in Washington
- Services include information and assistance, screening and assessment, consultation, respite care, support groups, and training and other resources to assist with caregiving tasks and experiences

- **Program expanded in SFY 2012**

- Initial funding was \$6.3 million. Program expanded by \$3.4 million, a 55% ↑
- Allowed program to provide a higher level of services to a greater number of caregivers screened for the program, and to serve caregivers with somewhat lower levels (but still high) of caregiving stress/burden



Family Caregivers are a vulnerable population

The **Family Caregiver Support Program (FCSP)** provides critical services for 8,600 unpaid family caregivers, only **1%** of family caregivers in Washington State.

The participating FCSP family caregivers:

- 55% are over age 60
- 31% work full or part time, and
- 50% scored high on depression scale

*WA State TCARE® Data



Family Caregivers are a vulnerable population

45% of FCSP caregivers report their own health status to be:

- Fair,
- Poor, or
- Very Poor

Statewide health data indicate that caregivers as compared to non-caregivers have:

- Have more physical and other limitations, and
- 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 2011 Department of Health BRFSS Data



FCSP Improves Outcomes for Family Caregivers

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



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”

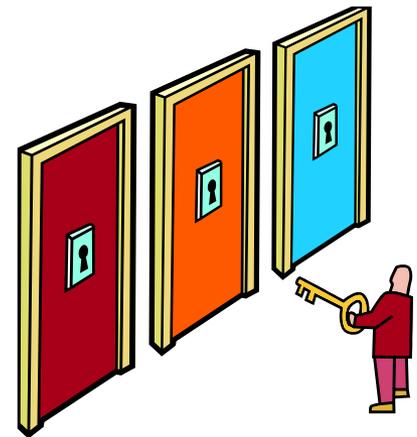


Family Caregiver Support Program

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



Family Caregiver Support Program

WA State TCARE[®] Data Demonstrates

Caregivers who did not continue in the FCSP (for variety of reasons) had come to the program too late to make a significant difference. They showed up with:

- The highest level of depression levels, and
- Were struggling with problem behaviors of their care receivers
- Their care receiver was more likely to enter Medicaid LTSS

Too little, too late!



Family Caregiver Support Program

To address Washington's age wave, we need additional investments to FCSP:

- Serve another 1% of state's unpaid family caregivers
- Increase dementia-capable practices and services
- Provide greater outreach and service to underserved populations
- Embed more evidence-based and effective practices statewide
- Improve TCARE® online capability to meet evolving needs
- Expand caregiver information, assistance and one on one consultation and care planning



WSIPP & RDA Reports on FCSP Expansion

WSIPP Report	RDA Report
Published November 2012	Published April 2014
Follow-up data available through FY 2012; median follow-up time for post-expansion group 5 months	Follow-up data available through FY 2013; all post-expansion group members have at least 12 months follow-up
The expansion resulted in a statistically significant delay in the use of Medicaid-paid LTSS, but due to short follow-up period, “this favorable result should be regarded as a tentative finding”	Using sufficient follow-up period, confirmed statistically significant delay in the use of Medicaid-paid LTSS



Higher screening rate, greater access to services post-expansion

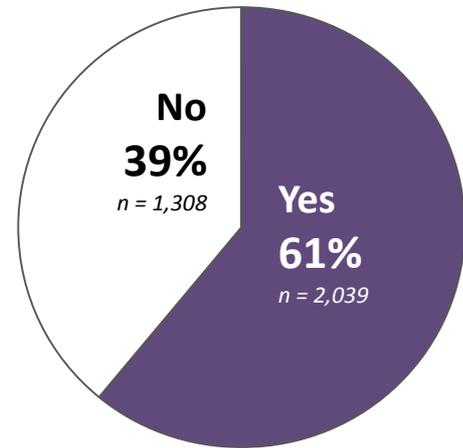
- The post-expansion period was half as long, but about the same number were screened
- Of those screened, a higher percentage went on to receive the higher level of services (for example, respite care, help with housework and errands)

Pre-Expansion

TWO YEARS: SFY 2010, 2011

TOTAL = 3,347

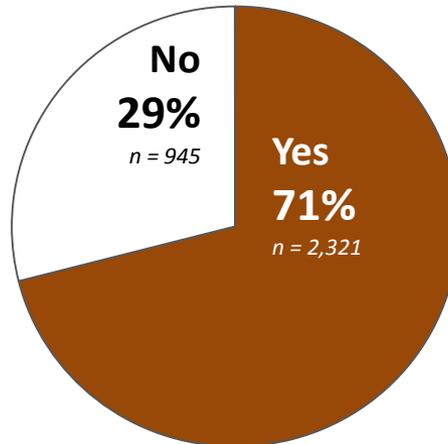
► *Received higher level of services?*



Post-Expansion

ONE YEAR: SFY 2012

TOTAL = 3,266



Family Caregiver Support Program Changes: Pre- versus Post-Expansion Differences

- Expansion met goal of serving caregivers “further upstream”
- Caregivers served at the higher level of care post-expansion had somewhat lower levels of stress and burden than those served pre-expansion...
 - TCARE® screen identified slightly fewer areas of significant caregiver burden
 - Care recipients slightly younger, less likely to have dementia
- ...but majority were still “high-intensity” caregivers.
 - Average post-expansion caregiver provided about 40 hours per week of care
 - 75 percent provided care for more than 1 year
 - About half of caregivers served post-expansion scored “high” on “stress burden” and on “depression”, respectively
 - Average age of care recipients 78 years
 - More than a third of care recipients had diagnosed dementia, and just over half had either diagnosed or suspected dementia



Family Caregiver Support Program Changes: Pre- versus Post-Expansion Differences

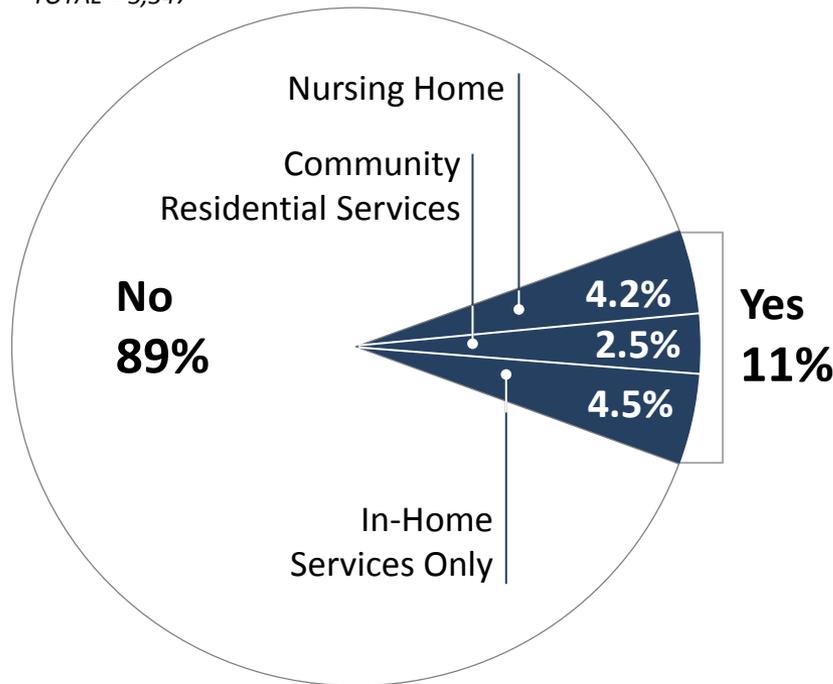
- Other notable differences:
 - Post-expansion FCSP caregivers provided care for more aging parents, fewer spouses
 - Post-expansion FCSP care receivers more likely to be enrolled in Medicaid medical coverage at time of TCARE[®] screen



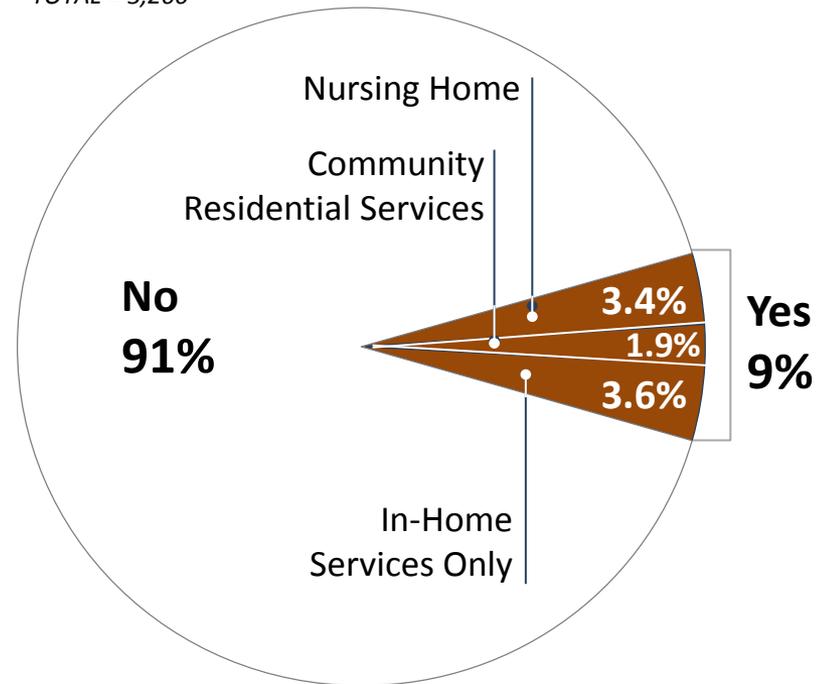
Use of Medicaid Long-Term Care in Year after Screening: Pre- versus Post-Expansion Comparison

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

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

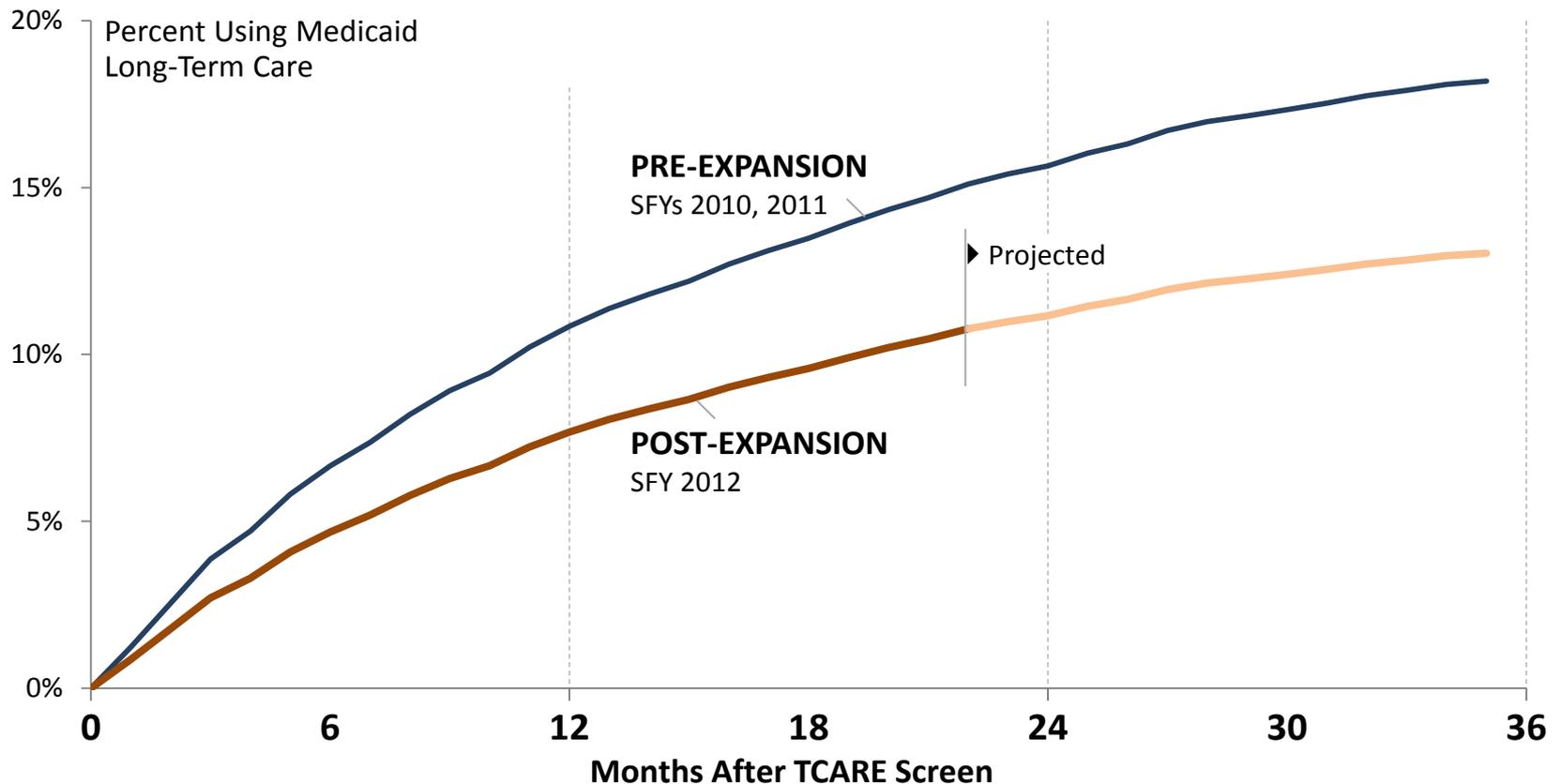


POST-EXPANSION
SFY 2012
TOTAL = 3,266



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



Summary of findings

- **Expansion increased access to FCSP services**
 - The volume of FCSP screening activity increased, and caregivers screened post-expansion were more likely to receive a full assessment and a broader range of support services than those screened in prior years
- **Expansion delayed transition to Medicaid long-term care services**
 - When access to FCSP services increased, utilization of Medicaid LTC decreased
 - This occurred despite the fact that more post-expansion care receivers were already enrolled in Medicaid medical coverage at time of screening

April 2014 | ADA Report 6-83
Olympia, Washington



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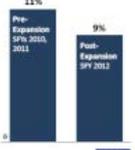
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Use of Medicaid LTC Services in 12 Months After First TCARE Screen



Screening Period	Enrollment Rate (%)
Pre-Expansion (SFY 2011)	11%
Post-Expansion (SFY 2012)	9%

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