

February 2012

PRELIMINARY REPORT: DID EXPANDING ELIGIBILITY FOR THE FAMILY CAREGIVER SUPPORT PROGRAM REDUCE THE USE OF LONG-TERM CARE?

In 1989, the Washington State legislature initiated the Respite Care Program, a statewide program focused on providing support to unpaid family caregivers. Building on this program, the Family Caregiver Support Program (FCSP), was established in 2000 to provide a more comprehensive array of information, resources and services to unpaid family caregivers caring for adults with functional disabilities.

In coordination with Washington State's 13 Area Agencies on Aging, the FCSP conducts tailored, guided, automated assessments of caregivers facilitated by trained Family Caregiver Specialists to measure the stress, depression, and other burdens associated with care giving. Based on assessments, the FCSP refers eligible caregivers to, or provides them assistance with:

- Education and training,
- Consultation,
- Counseling,
- Access to support groups,
- Respite care, and
- Other supportive services.

State and federal expenditures for the program in fiscal year 2011 were \$6.2 and \$2.7 million, respectively. In 2011, the legislature increased state funding for the FCSP for fiscal year (FY) 2012 for 1,500 new family caregivers and directed the Washington State Institute for Public Policy (Institute) to work with the Department of Social and Health Services (DSHS) to establish and review outcome data associated with the program.

The Institute and DSHS have identified outcome measures to determine if the assessment and support services provided to caregivers achieve one of the primary goals of the FY 2012 FCSP expansion—to delay placements of care recipients into costly Medicaid paid long-term care settings. The outcome measures are described in this report. A final report will be available by August 30, 2012.

Summary

A family caregiver voluntarily cares for a parent, spouse, partner, or another adult relative or friend. The assistance that family caregivers provide may allow care recipients to remain at home rather than in long-term care. Established in 2000, the Family Caregiver Support Program (FCSP) at the Department of Social and Health Services (DSHS) provides resources and services to unpaid family caregivers in Washington State. In concert with the state's 13 Area Agencies on Aging, the FCSP provides information and outreach; screening, assessment, consultation, coordination of services, and caregiver support services and resources. The program directly served 5,800 caregivers in fiscal year (FY) 2011.

The legislature increased funding for the FCSP by \$3.6 million for fiscal year 2012, to a total of \$12.5 million. FCSP estimates this additional funding will allow the agency to provide in-depth services to an additional 1,500 caregivers in the current fiscal year. The additional funding was based on assumed savings associated with delayed or avoided placements into costly Medicaid-paid long-term care.

The 2011 Legislature directed the Institute to work with DSHS to establish and review outcome measures associated with the FCSP expansion. The goal of the study is to assess whether the expansion of this program delays entry of care recipients into Medicaid-paid long-term care. Therefore, the Institute will focus its evaluation on the following Medicaid paid services:

- In-home services;
- Community residential services; and
- Nursing home services.

The Institute will estimate the cost-savings attributable to the FCSP and report its findings to the legislature in August 2012.

Suggested citation: J. Mayfield & M. Miller (2012) *Preliminary report: Did expanding eligibility for family caregiver support program reduce the use of long-term care?* (Document No. 12-02-3901). Olympia: Washington State Institute for Public Policy.

Family Caregivers in Washington State

For the purposes of this study, a family caregiver is a person who, without pay, cares for or supervises another adult: a parent, spouse, partner, other relative, or friend. According to statewide survey,¹ over 600,000 unpaid caregivers provided care for another adult in Washington State in 2007. The survey found that the primary challenges caregivers face are:

- Stress,
- Not enough time for self or family, and
- Impacts on family relationships.

In the survey, the greatest needs identified by caregivers were information on local programs (27 percent), money for supplies or equipment (24 percent), counseling (15 percent), and time off from care giving responsibilities (15 percent).

Washington State's Family Caregiver Support Program

In 1989, the state legislature funded respite services, that is, state-paid services that permit the unpaid caregivers to take time off from their care-giving duties. The Family Caregiver Support Program (FCSP) was established in 2000 to provide additional resources and services to unpaid family caregivers statewide. FCSP coordinates with the state's 13 Area Agencies on Aging (AAA) to provide the following services and assistance to unpaid family caregivers:

- Outreach and information on caregiving;
- Caregiver screening and needs assessment;
- Consultative and coordinated care plans tailored to caregivers' individual needs;
- Caregiver support services (paid and informal supports), such as:
 - ✓ Counseling, consultation, training and support group services;
 - ✓ Time off for caregivers (respite);
 - ✓ Referrals to health and wellness services; and
 - ✓ Resources to assist with physical barriers such as installing bath bars.

¹ Washington State Department of Health (2007) Behavioral Risk Factor Surveillance System (BRFSS).

Some of these services are provided through state and federal funding and others are paid for by local governments or philanthropic agencies, health insurance benefits, or natural support networks.

The Tailored Caregiver Assessment and Referral (TCARE[®]) System

In 2007, the legislature revised the laws regarding FCSP², directing DSHS to develop an evidence-based assessment and referral tool for the FCSP. In response to that mandate, in 2009, FCSP adopted and implemented the Tailored Caregiver Assessment and Referral (TCARE[®]) system,³ developed by Rhonda Montgomery at the University of Wisconsin-Milwaukee. The process aids the Family Caregiver Specialist and the caregiver in developing a coordinated care plan tailored to the specific needs of the caregiver.

The Washington State FCSP developed policies for a three-step process for caregivers interested in support to determine service eligibility and authorizations.

Step 1. Unpaid caregivers (self-referred or referred by another agency to the FCSP) are enrolled in TCARE[®], and receive information, referrals to community resources, and if needed, services up to \$250 (once annually). In fiscal year 2011, more than 5,800 caregivers received information and services at this point in the TCARE[®] process.

Step 2. For caregivers desiring to participate, a TCARE[®] screening is used to determine if caregivers are eligible for additional services and a more intensive TCARE[®] assessment. Approximately 2,200 new caregivers received this screening and up to \$500 in services in fiscal year 2011. The screen identifies and categorizes (High, Medium and Low) caregiver issues in the following five domains:

- Depression
- Relationship burden
- Objective burden
- Stress burden
- Caregiver identity discrepancy

² 74.41.050 RCW

³ For more information see: <http://www4.uwm.edu/tcare>. Further information is also available at the FCSP website: <http://www.aasa.dshs.wa.gov/Professional/TCARE/documents/TCARE%20Fact%20Sheet.pdf>

Step 3. Based on results of the TCARE[®] screening, some caregivers are eligible to receive a TCARE[®] assessment, followed by consultation and development of a care plan. This assessment is an in-depth structured interview conducted by a Family Caregiver Specialist; the screening, assessment, consultation and development of care plan take about four hours to complete. The TCARE[®] computer program is used to analyze the caregiver's responses. The computer program provides a profile of caregiver needs and suggestions for services that are tailored to the specific needs of the caregiver. The Family Caregiver Specialist then consults with the caregiver to develop a plan for ongoing services such as respite care, housework, and other assistance. Follow-up screenings and assessments depend on the circumstances of the caregiver.

During fiscal year 2011, a total of 1,381 new caregivers received a TCARE[®] assessment.

Funding for the Family Caregiver Support Program

One goal of the Family Caregiver Support Program is to delay or avoid placement of the care recipient in long-term care.⁴ The legislature anticipated that increased funding for FCSP would decrease the costs associated with more expensive Medicaid-paid long-term care by providing in-depth assessments and services to more caregivers. In FY 2011, expenditures for FCSP totaled \$8.9 million in (\$6.2 in state and \$2.7 federal). For FY 2012 (July 1, 2011 through June 30, 2012) the legislature increased the general state funding by \$3.6 million. FCSP will use most of the additional funding⁵ to provide assessment and consultation and tailored services (Step 3) for an additional 1,500 family caregivers.

The additional funding provided for fiscal year 2012 allowed FCSP to lower the eligibility thresholds for the TCARE[®] assessment and consultation (Step 3). Prior to the expansion, under state policy, new caregivers were eligible if the caregivers scored "High" in at least four of the five domains in the screen (Step 2).

⁴ State law (RCW 74.41.020) indicates that the FCSP is to "Encourage family and other nonpaid individuals to provide care for adults with functional disabilities at home, and thus offer a viable alternative to placement in a long-term care facility."

⁵ Of the \$3.6 million increase for FY 2012, \$150,000 was provided to expand the Memory Care and Wellness Services program.

Following the expansion, caregivers became eligible for the assessment if their screen indicates one "High" or three "Medium" scores.

The DSHS Aging and Disability Services Administration implemented additional FCSP policies and its Area Agencies on Aging partners began enrolling new, eligible family caregivers for the FCSP expansion immediately in July 2011. By the end of December 2011, midway through FY 2012, a total of 1,200 family caregivers had received a completed TCARE[®] assessment, consultation and care plan and were to receive follow-up comprehensive services.

Proposed Outcome Measures and Analysis

The 2011 Legislature directed the Institute to work with DSHS to establish and review outcome data for evaluation of the effects of the additional funding for FCSP. (See Exhibit 1.) The key outcome measures proposed for evaluating the FCSP are described in this preliminary report.

Exhibit 1 Legislative Direction

The 2011 Legislature directed the Washington State Institute for Public Policy "... to conduct a review of state investments in the family caregiver and support program. Funding for this program is provided by assumed savings from diverting seniors from entering into long-term care medicaid placements by supporting informal caregivers. WSIPP shall work with the department of social and health services to establish and review outcome data for this investment."

Second Engrossed Substitute House Bill 1087, Laws of 2011.

The FCSP expansion for FY 2012 is funded based on assumed savings associated with delaying Medicaid-funded long term care services. Therefore, the research question will be:

Did expansion of the FCSP program reduce the use of Medicaid-funded long term care services by care recipients?

Particularly, we will investigate whether expansion of FCSP is associated with delays in or avoidance of the following Medicaid-paid services for the care recipient:

- In-home services;
- Community residential services; and
- Nursing home services.

The Institute will estimate the average cost-savings associated with the delay in number of days to receipt of Medicaid-paid services attributable to FCSP services, and compare that estimate to the average cost of FCSP. The Institute will also attempt to describe program impacts on caregiver depression, stress, and other burdens.

The outcomes analysis will be based on a comparison of caregivers eligible for Step 3 (assessment and consultation) services and a statistically-matched group of similar caregivers who came close to, but did not meet, the minimum eligibility criteria for FCSP services. Several approaches to comparison group selection will be examined.

The analysis will rely primarily on data available from the TCARE® database, which began collecting data on caregivers in July 2009, along with Medicaid payment databases.

The DSHS Division of Research and Data Analysis will provide the Institute a database that combines caregiver information from TCARE® and other DSHS and Department of Health administrative data systems.

Next Steps

A final report describing the impact of the FCSP on the proposed outcomes and associated cost savings will be published by August 30, 2012.

For further information, contact Marna Miller
(360) 586-2745 or millerm@wsipp.wa.gov

Document No. 12-02-3901



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