FAMILY CAREGIVER SUPPORT PROGRAM
A REPORT ON THE FY 2012 EXPANSION

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Aging and Disability Services Administration | Department of Social and Health Services | State of Washington
P.O. Box 45600, Olympia, Washington 98504-5600 | 1.800.422.3263

The Washington State legislature has made important investments in supporting unpaid family caregivers for the past 23 years beginning with the creation of the statewide Respite Care Program in 1989. In 2000, the state Family Caregiver Support Program (FCSP) was established to provide a more comprehensive array of information, resources and services for unpaid family caregivers caring for adults (18+) with functional disabilities. The following year, federal funding also became available to support family caregivers through the Older Americans Act.

In 2007, the Washington State legislature required that ADSA adopt an evidence-based caregiver assessment for the FCSP. In collaboration with Washington's 13 Area Agencies on Aging (AAAs), ADSA selected the Comprehensive Tailored Caregiver Assessment and Referral (TCARE®) protocol, created by Rhonda Montgomery, PhD and colleagues at the University of Wisconsin-Milwaukee. The TCARE® protocol is designed to tailor services to the unique needs of each caregiver thereby reducing stress, depression and burdens associated with caregiving. TCARE® provides a consistent, objective and reliable screening and assessment process that identifies at-risk caregivers and targets resources to those most in need and determines whether support and services make a measurable difference to caregivers. TCARE® also helps inform policy through the collection of state-wide data.

The effectiveness of TCARE® is documented in published research articles based upon a national randomized control study, in which Washington State participated.

For more information, visit the national TCARE® website at www.TCARE.uwm.edu.

Washington State's Family Caregiver Support Program

Coordinated through Washington State's 13 Area Agencies on Aging, the FCSP provides the following services and assistance for unpaid family caregivers:

- Outreach and information on caregiving;
- Assistance finding help and accessing local services;
- Caregiver screening and assessment;
- Care plans tailored to caregivers' individual needs;
- Assistance accessing services and supports paid through state and other community resources such as:
  - Counseling, consultation, training and support group services;
  - Respite, or "time off" from caregiving responsibilities;
  - Referrals to health and wellness services;
  - Resources to assist with home care equipment or supplies, e.g., bath bars, incontinent briefs, etc.

In fiscal year 2012, $12.5 million in total was allocated to AAAs for the above services; state and federal allocations were $9.7 and $2.8 million, respectively.

From July 2009 to January 2010 significant staffing resources were dedicated to training, implementation and policy development related to TCARE® and their impacts on the FCSP.

From 2009 – 2011, the TCARE® screen was offered to all interested family caregivers. Due to budget limits, the full TCARE® protocol, which includes a caregiver assessment, consultation and care planning along with a more comprehensive set of services, was made available only to those family caregivers at the very highest levels of stress and burden.

Recognizing the need to better serve family caregivers - *before* they are completely exhausted and close to placing their loved ones in a LTC facility - the legislature increased state funding for the FCSP for fiscal year (FY) 2012, by $3.45 million. The intent of the expansion funding was to reach out to and serve family caregivers who were experiencing depression, stress, and/or other types of burden but were not yet eligible to receive a full TCARE® assessment/care plan and related services under the previous criteria. The additional funding assumed savings that would be achieved by diverting care receivers from more costly Medicaid long term care services.

FY 2012 FCSP expansion funding allowed for 1,500 new family caregivers to receive the full TCARE® protocol, and directed the Washington State Institute for Public Policy (WSIPP) " … to conduct a review of state investments in the Family Caregiver Support Program (FCSP). Expansion funding for this program was provided by assumed savings from diverting seniors from entering into long-term care Medicaid placements by supporting informal caregivers."

"Without the Family Caregiver Support Program I would have been sunk!"

What Changes Were Made Based Upon the Expansion Funding?

When the TCARE® system was first launched statewide, ADSA and its AAA partners developed comprehensive policies for implementation. A team of staff from ADSA and AAAs decided how to implement the new protocol and established restrictive criteria for assessments and costlier services in response to budget constraints.

A portion of the TCARE® protocol was adapted for use as the "TCARE® Screen" that helps identify which caregivers should move on to a full assessment. The TCARE® Screen measures caregiver depression, relationship, objective, and stress burdens as well as caregiver identity discrepancy. The responses feed into scores related to levels of risk (Low, Medium, and High) in each of the five previously listed domains.

Caregivers with high enough scores on the TCARE® Screen (as determined by policy and available funding) are offered the TCARE® Assessment, which includes questions more focused on the person for whom the caregiver is providing care. Upon completion of the assessment, the TCARE® algorithm develops a profile of caregivers' needs and provides recommendations for services tailored to reduce their stress and burdens. Using these results, a Family Caregiver Specialist consults with the caregiver to develop a "care plan" for ongoing services. The screening, assessment, consultation and care plan together take about four hours to complete. Washington is the first state to automate this process through custom-built software.

In the first 2 years of TCARE® implementation, i.e., before the FY 2012 expansion, state policy was to require 4-5 High scores on the Screen in order to move on to the TCARE® Assessment.

As of July 1, 2011 new criteria, either 1 High or 3 Medium scores on the TCARE® Screen, allowed the caregiver to move on to the full TCARE® protocol. This change enabled the FCSP to reach caregivers at a time when it is still possible to impact the health and burdens of the caregiver and is more consistent with the national TCARE® protocol and research.

Activities Accomplished

With a quick ramp-up needed for the WSIPP study, the FCSP Expansion required a series of tasks to be implemented on a short timeline. In order to serve up to 1,500 new caregivers within a 6-7 months period, AAAs were each expected to reach and serve specified numbers of family caregivers with the full TCARE® protocol.

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To serve the increased number of caregivers, new staff had to be hired at the AAAs or other community service partners, and many staff had to be certified to administer the evidence-based TCARE® protocol. The TCARE® certification process, managed by the University of Wisconsin-Milwaukee, includes an intensive, on-site, three day training plus assessment practice and online testing; it can take up to six weeks for staff to be certified. Certification is critical to the fidelity of the evidence-based protocol. ADSA certified 50 new TCARE® Assessors to conduct assessments, consultation and care plans.

In addition:

- ADSA staff developed and trained FCSP staff statewide on new policies for the FCSP expansion.
- Fourteen trainings took place statewide (July and August 2011) to educate DSHS Home and Community Services (HCS) staff - including intake, financial, social workers, etc. - about the FCSP.
- A referral system was created for HCS staff, who answer inquiries about and accept application for Medicaid, to refer family caregivers whose family members were either not yet enrolled in or eligible for Medicaid long-term care (LTC) services, to the FCSP. HCS staff referred more than 500 family caregivers to local programs.
- FCSP staff was required to collect and document the care receivers' financial resource information for the first time.

While the FCSP focus has always been on improving outcomes for the family *caregivers,* i.e., reducing their depression, stress and burdens, the expansion and the WSIPP study brought a new element into the mix: outcomes for the *care receivers* were to be measured in terms of preventing or delaying their enrollment in Medicaid LTC services.

More than 850,000 unpaid family members provide care for adults in Washington. The value of this informal care is $10.6 billion dollars annually.

AARP Public Policy Institute

The FCSP Is A Multi-Component Program

The FCSP offers family caregivers a variety of strategies for support based on a family's particular situation and preferences. Some families who contact the FCSP are only looking for timely and critical information about community resources or educational opportunities, and thereafter rely on informal support networks or pay privately for assistance. Others need professional guidance in understanding their needs and options. Still others need short-term (e.g., training or counseling) or ongoing direct services (e.g., access respite care services through a sliding-fee scale). The FCSP was designed to assist families in any of these situations.

Figure 1 below outlines the different levels of service available to families in Washington's FCSP.

"Thank you so much. I feel like a huge weight has been lifted off my shoulders."

Figure 1. FCSP Offers Varied Types and Levels of Assistance and Services

	Caregiver Need/Risk levels	TCARE® & Support Services Available	In FY 2012
Step 1	Unpaid caregivers who call the local FCSP and receive information, referrals to community resources, and services.	Depending on needs, these caregivers may be entered into the TCARE® on-line system and offered services, up to a value of $250 (once annually).	1518 new caregivers received information and limited services.
Step 2	Caregivers who need additional support/s are offered a TCARE® Screening/Personal Caregiver Survey, the results of which are used to determine eligibility for the full TCARE® assessment and access to a more robust service package	Complete TCARE® Screening, and depending on eligibility, may receive services up to $500. Examples might include short-term counseling or training, access to incontinent supplies, etc.	Approximately 859 new caregivers received the TCARE® Screening and services without going further in the TCARE® process
Step 3	Caregivers at greater risk are eligible to receive the full 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/Assessor.	Complete TCARE® Assessment, and depending on needs, receives tailored services, such as respite care, housework, trainings, and other assistance. At least every 6 months, follow-up screenings and annually, assessments are conducted to help determine how caregiver is doing and changes to the plan of care.	2273 new caregivers received a TCARE® Assessment and/or care plan and tailored services.

What Were the Results of the FCSP Expansion?

The Washington State Institute for Public Policy (WSIPP) released its report from the FCSP expansion on November 21, 2012. Preliminary findings indicate that **the expansion resulted in a statistically significant delay in the use of Medicaid LTC services.** The short timeframe did not allow for direct measurement of the Medicaid LTC costs associated with the expansion, so an alternative method to estimate the maximum possible savings was used. Findings suggest it is unlikely that the expansion would pay for itself in the first year of the expansion. A longer term study was recommended.

The WSIPP study reported on only one facet of the expansion – the impact on Medicaid LTC costs experienced by the care receiver.

The FCSP Expansion reached the targeted number (1,500) of new family caregivers with the full TCARE® protocol. Another positive finding is that the expansion reached the targeted caregivers - those with a somewhat lower level of stress and burden at initial assessment (vs. caregivers at initial assessment prior to the expansion).

The WSIPP study was narrowly focused by design and did not address outcomes for family caregivers who experienced the full TCARE® protocol.

ADSA, however, has accrued additional data - shared in the next section – which sheds light on the program's effectiveness in helping family caregivers.

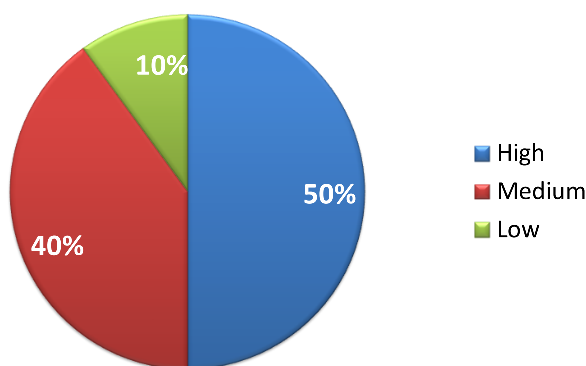
"I couldn't handle caregiving without you and the FCSP."

What Did We Learn About the Caregivers Served Under the Expansion?

An analysis of characteristics of family caregivers who were served through the FCSP expansion, paint a picture of a highly vulnerable caregiver population.

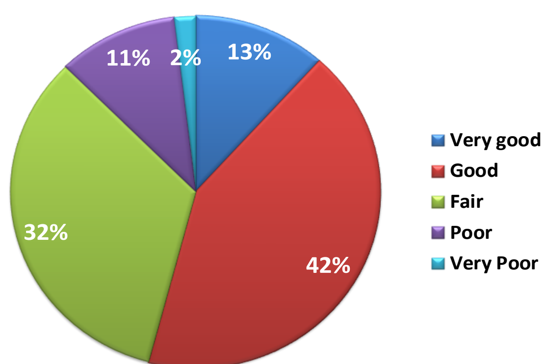
- Fifty percent (50%) of family caregivers are considered to be at 'high' levels of depression.
- Forty five percent (45%) of caregivers rated their health as fair, poor or very poor.
- Forty percent (40%) of caregivers are caring for a person with medically diagnosed Alzheimer's or dementia; another 14% care for a person with probable Alzheimer's/dementia, not diagnosed.

Caregiver Depression



Note: Based on the 10 question Center for Epidemiologic Studies Depression (CESD) measure
From: ADSA TCARE Database 2012

Overall Health of Caregivers



Note: Assessment Question - How would you rate your overall health at the present time?
From: ADSA TCARE Database 2012

Poor Health of Caregivers Leads to Higher Health Care Costs

A 2011 study released by the National Alliance for Caregiving adds to prior research that the health of family caregivers can be negatively affected, particularly as caregiving continues over time. The study investigated health care costs of those caring for a person with Alzheimer's disease.

Findings of the study reveal that caregivers' self-reported health declined steadily and significantly over the 18 months of study. This decline in health was evidenced by services provided in emergency room and hospitals – which doubled over the time period, and in increased use of all type of health care services.

Healthcare costs for those caring for a person with Alzheimer's was an average of $4,766 more per year than for non-caregivers.

The best predictor of increased health care utilization was the caregivers who had rated their own health **as "fair or "poor"** at the outset of the study.

"Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient", National Alliance for Caregiving, November 2011

Companies pay 8% more in healthcare costs for workers with caregiving responsibilities than for those who are non-caregivers.

"Understanding the Impact of Family Caregiving on Work", AARP Public Policy Institute, October 2012"

What Else Did We Learn About the Caregivers Served?

- More than half of caregivers (52%) say they would consider placement for their loved one out of the home if their situation worsens.
- Thirty-six percent (36%) of caregivers have been providing care for five or more years
- More than half (55%) of caregivers are 61 years or older.
- Thirty-one percent (31%) work full- or part time

"If it hadn't been for in-home respite through the FCSP, I would have had to place my parents. I wish I had heard about the program years ago."

How Many Care Receivers Are Potentially Eligible for Medicaid LTC Services?

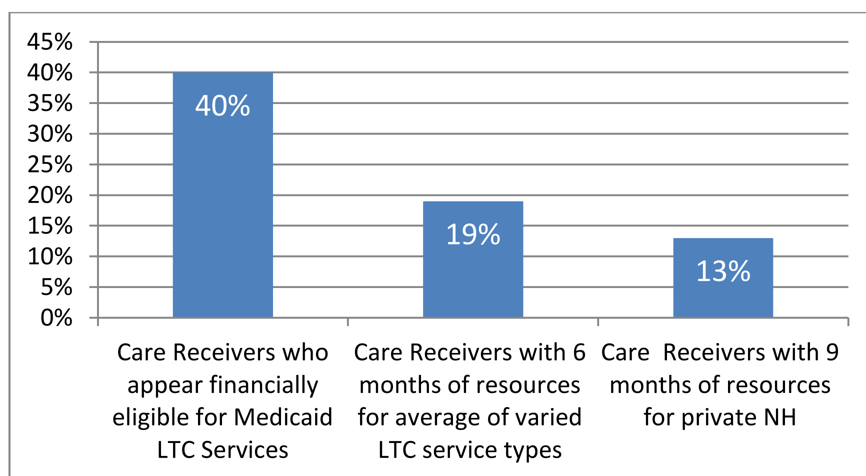
Of particular interest to ADSA is the number of families served in the FCSP whose care receivers are at imminent risk of spend-down to Medicaid-funded long term care services, including nursing homes.

Many care receivers, while both functionally and financially eligible, may not access Medicaid LTC for a variety of reasons. These potentially eligible care receivers could, though, given their characteristics and reliance on a family caregiver, begin to access LTC services and/or spend down to Medicaid at any time.

Prior to the FCSP Expansion, ADSA did not collect resource information of the care receiver. In order to better understand the size of this potentially eligible population, ADSA required at the outset of the expansion that Family Caregiver Specialists document the financial resources of the care receiver.

At the time of the TCARE® Caregiver Assessment, 40% of care receivers appeared already financially eligible for Medicaid Long Term Care services**.** An additional nineteen percent (19%) of care receivers had resources equivalent to 6 months' worth of LTC services (based on an average of all types of LTC services including in-home, residential and nursing home care). Another 13% would spend-down to Medicaid eligibility within 9 months if they were to use a nursing home (NH).

Figure 2. Care Receivers Financially Eligible for Medicaid Long-term Care



From: ADSA Database 2012.

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We also know that of the caregivers who received a caregiver assessment, 76% of the persons they were caring for look to be functionally eligible for Medicaid LTC services.

For this significant potentially eligible group, the FCSP is serving as a viable and preferred option for families who are striving to keep a loved one at home and cared for by a family member who is unpaid. Many of the family caregivers, as noted earlier have compromised health and/or high levels of depression. And, providing supportive caregiver services to these vulnerable primary caregivers is a way to divert these care receivers from the Medicaid LTC system.

This new data on the caregiver/care receiver group highlights the critical need to stay the course in offering tailored supports that both prevent and address caregiver depression, stress, and burdens so they can remain physically and emotionally healthy themselves *as well as* continue caring for their loved ones.

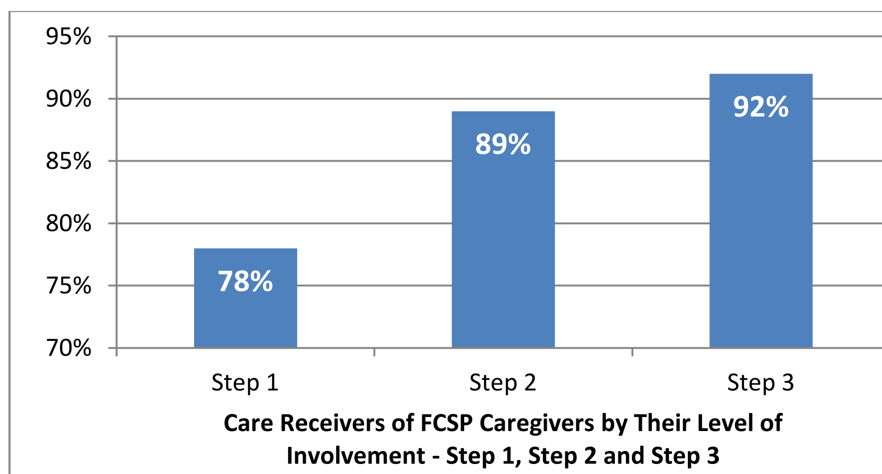
"I wanted to let you know how much your program has impacted my ability to care for my mother….No one, who hasn't cared for an aged dementia-victim, could possibly know how difficult it is."

Is the Investment in the Full TCARE® Protocol Advantageous?

ADSA TCARE® data reveal that the more vested a family caregiver/care receiver dyad is in the TCARE® process, the less likely the care receiver is to end up utilizing Medicaid Long Term Care service utilization.

Figure 3 shows the care receivers of caregivers who participated at each level of the FCSP (Step 1, 2 and 3) in terms of their subsequent Medicaid LTC service utilization. Refer back to Figure 1 for description of each step. Those families that completed the full TCARE® process (Step 3: assessment, consultation and care plan), had care receivers who were more likely to still be at home and on the FCSP – and *less likely* to enter into Medicaid LTC services.

Figure 3. **FCSP Care Receivers Still at Home and Not Receiving Medicaid LTC**



From: ADSA Database 2012.

Note: Includes caregivers who entered FCSP as of July 1, 2011; the analysis shows subsequent Medicaid LTC service use for their care receivers as of June 30, 2012.

Step 1 reflects 1518 caregivers linked with a care receiver, with another 274 caregivers without linkage to care receivers; Step 2 includes 859 caregivers; Step 3 includes 2108 caregivers who received care plans.

This data suggest that implementing the full TCARE® process (Step 3) with family caregivers is of benefit in terms of diverting their care receivers from Medicaid LTC service utilization.

From ADSA's perspective, the FCSP Expansion with its focus on making the full TCARE® process available to family caregivers at high and moderate stress and burden levels appears to preserve the full and originally intended level of benefit of the TCARE® protocol.

Is the FCSP Making A Difference for Family Caregivers?

A recent investigation by Rhonda Montgomery, PhD and colleagues focused on Washington's TCARE® data reveals that family caregivers who participate in the full TCARE® Assessment and continue to be served in the FCSP 6 months later demonstrate positive changes.

More specifically:

- For spouse caregivers: despite increasing assistance needed by their care receivers in terms of Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and behaviors over a 6-month period, spouse caregivers showed lower Objective Burden, Stress Burden, Identity Discrepancy and Depression at statistically significant levels.
- For adult child caregivers: while IADL needs increased over a 6-month period, Stress Burden and Depression were significantly lower.

"The patterns show that outcomes are going in the right direction", says Rhonda Montgomery, PhD, "The real pay-off comes when we reach families before they are in crisis. When we do this, we see that even as the needs of the care receiver increase, the ongoing support and services make a difference – and caregivers can hang on longer. Much of the benefit comes from this focus on reduced depression for caregivers. The bottom line is that we can make a difference in the lives of caregivers if we offer them the right support at the right time…before it's too late."

Next steps

- Sustain funding for the Family Caregiver Support Program at the current expansion levels.
- Advocate for implementation of WSIPP recommendation of a longer-term study of impacts related to Medicaid diversion and savings.
- Continue to target higher level of services to those caregivers/care receivers at high risk.
- Evaluate policies with Family Policy Team in light of WSIPP recommendations around targeting of FCSP.
- Implement a standardized satisfaction feedback survey with family caregivers utilizing the program.
- Implement new system of tracking services used by each caregiver (i.e., ASIS).
- Consider study on outcomes of the family caregiver support program that go beyond solely Medicaid diversion for care recipients, which might include outcomes related to level of assistance (Step 1, 2, 3), specific service use, and/or the impact of caregiving on employment, family caregivers' health outcomes and health care costs.

- Promote further integration of evidence-based practices known to impact caregiver stress, depression, care receiver behaviors and/or nursing home placement (e.g., STAR-C, Reducing Disability in Alzheimer's Disease, Powerful Tools for Caregivers, Memory Care & Wellness Services, etc.)
- Explore mechanisms, beyond FCSP, to increase supports for individuals/care receivers who are at imminent risk of nursing home placement and Medicaid spend-down.

Conclusion

ADSA is grateful for the opportunity presented by the Family Caregiver Support Program (FCSP) Expansion. The Washington State Institute for Public Policy (WSIPP) study and the internal work of ADSA and AAAs have allowed the FCSP to not only serve more family caregivers but to implement, evaluate and consider strategic refinements and improvements to the program.

As the population of individuals needing caregiver support increases, including the number of adults age 65 and over in Washington which will double in the next twenty years, the need to invest in evidence-based and cost-effective practices that help people stay in their homes and communities - where they most want to be - is critical.

In moving forward, it is essential to recognize that the Family Caregiver Support Program impacts the health and well-being of both the family caregiver and the care receiver. To this end, broadening the scope of measured outcomes, effectiveness and ultimate value of the program is critically important in considering future funding and evaluation efforts.

For further information, contact:
Susan Engels, Chief, State Unit on Aging
EngelSS@dshs.wa.gov
(360) 725-2527