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DID EXPANDING ELIGIBILITY FOR THE FAMILY CAREGIVER SUPPORT PROGRAM PAY FOR ITSELF BY REDUCING THE USE OF MEDICAID-PAID LONG-TERM CARE?

In 1989, the Washington State Legislature initiated the Respite Care Program, a statewide program focused on providing public support to eligible, unpaid family caregivers. The legislation marked the first time that unpaid family caregivers were regarded as the clients of a state-paid, long-term care service.

Building on this program, in 2000 the Family Caregiver Support Program (FCSP) was established to provide a more comprehensive array of information, resources and services to unpaid family caregivers attending to adults with functional disabilities. In coordination with Washington State's 13 Area Agencies on Aging, the FCSP screens and conducts assessments of caregivers facilitated by trained Family Caregiver Specialists to measure the burdens associated with care giving. Based on the assessments, the FCSP refers eligible caregivers to, or provides them with assistance for, the following:

- 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 (FY) 2011 were $6.2 and $2.7 million, respectively.

In 2011, the Legislature increased state funding for the FCSP for FY 2012 by $3.45 million to serve up to 1,500 new family caregivers. The Legislature also 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.

In this report, we describe the population of caregivers served by the program, how the expansion was implemented, and provide a preliminary estimate of the effect of the expansion on the use of Medicaid long-term care (LTC) by care recipients.

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. The Family Caregiver Support Program (FCSP) at the Department of Social and Health Services (DSHS), in concert with the state's 13 Area Agencies on Aging, provides information and outreach, screening, assessment, and caregiver support services to unpaid family caregivers in Washington State.

To expand the program to serve more caregivers, the 2011 Legislature increased funding for the FCSP by $3.45 million for fiscal year 2012. The additional funding was based on assumed savings associated with delayed or avoided placements into more costly Medicaid-paid long-term care (LTC).

The 2011 Legislature directed the Washington State Institute for Public Policy to work with DSHS to review outcome measures associated with the FCSP expansion. The goal of the study was to assess whether the expansion of this program delayed or reduced entry of care recipients into LTC and thereby reduced LTC costs.

The short legislative timeline for this study precluded a comprehensive evaluation. Nonetheless, based on the limited data available, we report two preliminary results.

First, it appears that the expansion significantly delayed the use of LTC. Because of the very short follow-up period, however, this favorable result should be regarded as a tentative finding.

Second, because the short timeframe did not allow us to directly measure the LTC costs associated with the expansion, we adopted an alternative method to answer the legislative question of whether expanding eligibility for the FCSP paid for itself. Even if the expansion was 100% successful in avoiding LTC costs, we estimate the maximum possible state savings would have been $1.67 million in the first year. Since $3.45 million was budgeted for the FCSP expansion, it appears unlikely that the expansion would have been cost neutral, at least in the first year, as assumed in the budget.

We recommend that a longer term evaluation of the expansion be conducted to determine if benefits match costs over an extended period.

Suggested citation: Miller, M. (2012). *Did expanding eligibility for family caregiver support program pay for itself by reducing the use of Medicaid-paid long-term care?* (Document No. 12-11-3901). Olympia: Washington State Institute for Public Policy.

BACKGROUND ON THE PROGRAM

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 a recent statewide survey by the Washington State Department of Health,[1] over 600,000 unpaid caregivers provide care for another adult in Washington State. The survey found that the primary challenges caregivers face are:

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

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

WASHINGTON STATE'S FAMILY CAREGIVER SUPPORT PROGRAM

In 1989, the state Legislature funded "respite services"─ state-paid services that permit eligible unpaid caregivers to take time off from their care-giving duties.

The initial respite care program was modified in 2000 by the creation of the Family Caregiver Support Program (FCSP) 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.

Some of these services are provided through state and federal funding and others are paid 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 FCSP, directing DSHS to identify an evidence-based assessment and referral tool for the FCSP.[2] In response, 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. In one study, conducted by the developer of the system, the TCARE protocol was found to reduce caregiver burdens, depressive symptoms, and intention for nursing home placement.[4] The effect of TCARE on LTC use or cost, however, has not yet been studied.

As part of TCARE implementation, DSHS developed a three-step service eligibility and authorization process. This was done to ensure available resources were targeted to caregivers most in need. This process was a Washington alteration to address funding constraints and is not related to the TCARE protocols.

Step 1 Community resources and information. 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 per year. In fiscal year 2011, more than 5,800 caregivers received information and services at this point in the TCARE process.

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

[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

[4] R.J.V. Montgomery, J. Kwak, K.O. Valuch, & K. Kosloski. (September 01, 2011). Effects of the TCARE intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 5, 640-647.

Step 2 TCARE Screen. 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 2,300 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; and
- Caregiver identity discrepancy.

Step 3 TCARE Assessment and Consultation. 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.

EXPANDED 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.[5] The legislature expected that increased funding for FCSP could decrease the costs associated with more expensive Medicaid-paid long-term care (LTC) 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, the legislature increased the state funding by $3.45 million.[6]

In FY 2012 FCSP used most of the additional funding to provide assessment and consultation and tailored services (see Step 3) for up to 1,500 additional family caregivers whose care receivers were not currently receiving Medicaid LTC services and had not previously had a TCARE screen or assessment.

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).[7] 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 June 2012, a total of 2,407 new family caregivers had completed a TCARE assessment.

Because federal funds pay half the cost of Medicaid LTC, in order for the $3.45 million FCSP expansion to be cost-neutral for the state, the expansion would have to reduce total LTC expenditures by twice this amount—to a total of $6.9 million. The budget for the program assumed that this cost offset was possible in the first year of operation. This report describes our preliminary analysis of this question.

[5] 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."

[6] For FY 2012, the legislature provided an additional $3.6 million to FCSP, of which $3.45 million was provided to expand eligibility for TCARE and $150,000 was allocated to expand the Memory Care and Wellness Services program.

[7] Some AAAs lowered the eligibility criteria for an assessment to 3 high burdens prior to the expansion

STUDY QUESTIONS AND DESIGN

The 2011 Legislature directed the Institute to work with DSHS to evaluate the effects of the additional funding for FSCP. (See Exhibit 1.)

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. The five research questions for this study are:

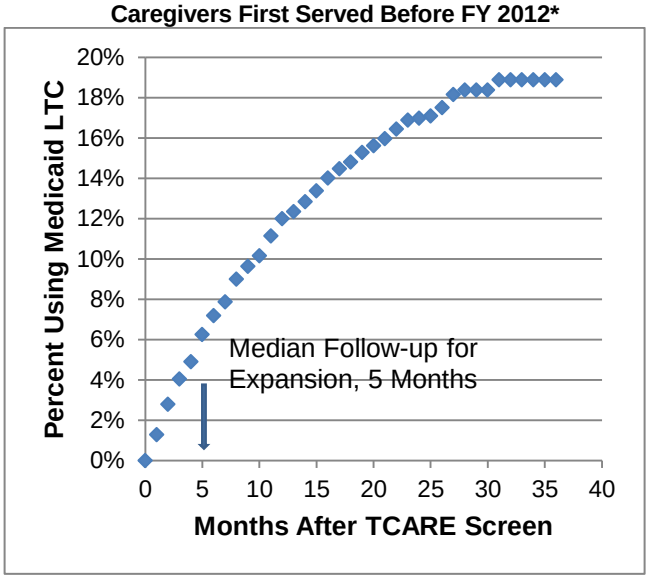
1) Who were the caregivers served by the expansion? Did they differ from the group of caregivers served prior to the expansion?
2) In the period prior to the expansion, how frequently did care receivers use Medicaid LTC? How often was the LTC in residential versus in-home care?
3) Did expansion of the FCSP program delay the use of Medicaid-funded long-term care services by care recipients?
4) Did expansion of the FCSP program reduce the use of Medicaid-funded long-term care services by care recipients? Did the expansion reduce LTC costs equivalent to the state investment in the expansion?
5) What characteristics are associated with increased used of Medicaid LTC?

STUDY DESIGN

To study these questions, we collected information recorded in the TCARE database. Staff at DSHS Research and Data Analysis matched the care recipients to Medicaid records to identify Medicaid expenditures for long-term care and enrollment in the Medicaid medical program. Care recipients were also matched to Department of Health death records.

For this analysis, we have complete information on the use of Medicaid LTC through April 2012. This allows a maximum follow-up period of only 10 months for those in expansion group; for most analyses, the short follow-up requires that we omit those caregivers served in the last two months of the expansion. The median follow-up for the expansion was five months. That is, half of those served by the expansion had a follow-up period of five months or less. As can be seen in Exhibit 2, the percentage of the FCSP population prior to FY 2012 that had used any LTC increased sharply over the first 30 months after the screen. Thus, we were unable to see a complete picture of how the expansion may have affected the later use of Medicaid LTC.

Exhibit 2
Time from First TCARE Screen Until First Use of Medicaid Long-Term Care
Caregivers First Served Before FY 2012*



*Based on results of survival analysis.

Ideally, an evaluation of this expansion would have included random assignment of caregivers to access to the TCARE assessment (Step 3) and we would have had a follow-up period of sufficient length to observe changes in the LTC usage by care receivers. However, random assignment was not included in the legislation, and the legislature desired a report in advance of the fall 2012 budget drafting. Therefore, in lieu of direct measurement, we take several approaches to estimate likely effects of the expansion.

In our analysis, we focus on caregivers with their first TCARE screen.[8] We then took several approaches to estimate the effect of the FCSP expansion on the use of Medicaid LTC.

- We used a statistical method called survival analysis which allows us to compare groups with varying follow-up periods. Using the entire population that received a TCARE screen (including those with assessments) we measured the effect of the expansion on time to use of LTC, compared with those served before the expansion.
- In discussions with legislative and program staff we learned that it was presumed that the expansion would be able to recoup the investment in one year. Because the follow-up was too short to actually measure LTC costs for the expansion, we took an alternative approach to project what the maximum benefits would likely be, based on those caregivers served in the pre-expansion period. The major change that occurred in the expansion was increasing access to assessments by reducing the burden threshold. Thus, to estimate the effects of providing assessments to this broader group of caregivers, we added up the total cost of Medicaid LTC in the first 12 months following the initial screen for caregivers who had not received an assessment. Then we estimated the total LTC costs that might be incurred by the expansion population in the first year after the screen.
- We use the entire pre-expansion population (those with and without assessments) to identify those caregiver characteristics associated with increased LTC costs.

[8] The expansion was designed to serve caregivers new to the TCARE system. Therefore, all of our analyses focused on caregivers receiving their first TCARE screen.

FINDINGS

In Exhibit 3, we show, by fiscal year, the number of caregivers who received a TCARE screen and those who also received an assessment. In FY 2012, the year of the expansion, about 1,400 more new caregivers received a screen and assessment than in the preceding year. Expansion did, in fact, take place.

Exhibit 3
New Caregivers Served by FSCP*

Fiscal Year	Caregivers Served	
	Screens	Assessments
2010	1,476	1,028
2011	2,354	1,042
2012	3,430	2,407

*Numbers in Exhibit 3 omit those caregivers served by the Nursing Home Diversion Project and the Memory Care and Wellness Services Program, as well as those receiving any Medicaid LTC at the time of the TCARE screen.

Research Question 1. Who were the caregivers served by the expansion? How did they differ from the group of caregivers served prior to the expansion?

A profile of caregivers receiving assessments prior to and during the expansion is provided in Exhibit 4. The average caregiver with an assessment in FY 2012 was significantly different on most characteristics from those served prior to the expansion. Consistent with the lowered eligibility for assessment, compared to those with screens before the expansion, those served during FY 2012 reported lower levels of burden. They were less likely to be the spouse of the care receiver. On average, they were also younger; they reported fewer hours per week spent in care-giving and shorter time providing care for the recipient. Care recipients of those assessed during the expansion were more likely to be enrolled in the Medicaid medical program than those initially served in the two previous years.

Exhibit 4
Caregivers Receiving First Assessments‡

	Before FY 2012	Expansion (FY 2012)
Number of caregivers/receivers	2,070	2,407
Total number of "high" burdens	3.12	2.76
High relationship	45%	38%
High objective	69%	55%
High stress	60%	53%
High depression	59%	51%
High discrepancy	80%	79%
Caregiver is caring for:		
Spouse	57%	48%
Parent	34%	40%
Child	1%	1%
Other	8%	10%
Caregiver Age		
Less than 30 years	2%	3%
30-45 years	7%	10%
46-60 years	29%	33%
61-75 years	39%	36%
Over 75 years	23%	18%
Diagnosed Dementia	42%	38%
Hours per week caring for relative	39.5	21.1
How long providing care?		
Less than 6 month	9%	13%
6 to 12 months	9%	12%
13 to 24 months	12%	15%
24 month to 5 years	30%	29%
Over 5 years	39%	31%
Definitely would consider move to out-of-home setting	7%	7%
Enrolled in Medicaid medical	7%	10%

‡With the exception of the response "Definitely would" to the question, "Given your care receiver's CURRENT CONDITION, would you consider having him/her move to an out-of-home, long-term care setting?" all differences between the pre-expansion period (before FY 2012) and the FCSP expansion, FY 2012, are statistically different at $p<0.01$.

Research Question 2. What LTC services were used by care receivers in the 12 months after the TCARE screen?

Ideally, we would compare the use of LTC services for those in the expansion with LTC services for those with TCARE screens prior to the expansion. As mentioned earlier, however, the very short follow-up period precluded such a comparison for this report. Here we report on the use of LTC by those served prior to the expansion. As shown in Exhibit 5, during the pre-expansion period, 10.5% of care receivers had some type of Medicaid-paid LTC service in the 12 months following the initial TCARE screen. Of those, half received only residential care (nursing homes, adult family homes, or assisted living). The remainder received in-home services or a combination of in-home and residential services.

Exhibit 5
Use of Medicaid LTC in 12 Months After First TCARE Screen (Pre-Expansion Caregivers)

Number of Care Recipients	3,037
No LTC	89.5%
Any LTC	10.5%
Residential only	5.0%
In-Home Services only	4.5%
Both In-Home and Residential	1.0%

Research Question 3. Did expansion of the FCSP program delay the use of Medicaid-funded long-term care services by care recipients?

To answer this question, we used a statistical method referred to as survival analysis. Survival analysis allows us to compare the time to use of Medicaid LTC by those in the expansion group with those first served in the two years prior to the expansion. The analysis allows us to control for characteristics that might influence the use of LTC, so that we can estimate—all else being equal—whether the expansion affected the time to LTC.[9]

Based on the relatively short follow-up period, we found that the expansion had a statistically significant impact in delaying the use of Medicaid LTC.[10] We consider these to be tentative findings because, as noted, the median follow-up period was only 5 months for the expansion compared with 15 months for the pre-expansion group. This favorable preliminary finding—that the expansion delayed the use of LTC—can only be confirmed if a longer-term evaluation is undertaken.

[9] The analysis controlled for whether the caregiver was the spouse, the number of high burdens reported, whether the care recipient was enrolled in the Medicaid medical program at the time of the screen, and whether she or he would "Definitely would consider" moving the care receiver to an out-of-home setting. These factors were identified as affecting the use of LTC in earlier analysis.

[10] Results of the Cox survival analysis are provided in Exhibit A3.1 in the Appendix.

Research Question 4. Did expansion of the FCSP program reduce the cost of Medicaid-funded long-term care services for care recipients? If so, was the reduction sufficiently large to offset the cost of the expansion?

Based on the survival analysis, the use of LTC was apparently delayed by the expansion. We assume that the delay translated into a reduction in LTC expenditures. However, because of the short follow-up for the expansion, we could not answer these questions directly.

As mentioned earlier, the budget for the expansion assumed the LTC savings in the first year would be sufficient to offset the cost of the expansion. Because of the short follow-up period, however, we were unable to measure a full year's LTC costs or savings. Instead, we took an alternative approach to estimate the maximum cost savings that might be observed for the expansion group in the 12 months after the initial TCARE screen, based on those in the pre-expansion group who did not receive assessments. We included those caregivers who received a TCARE screen prior to May 2011. (This allowed us to look at total LTC costs in the 12 months following the screen.)

We used a two-stage approach. First, we ran regression analyses to identify the impact of caregiver characteristics on the LTC costs incurred in the 12 months after the initial screen. Second, we applied information from the regression analysis to the population mix served in the expansion. Using this approach, we estimated the average total LTC cost per care recipient would have been $972 in the 12 months following the TCARE screen.[11] An additional 3,430 caregivers received a screen in FY 2012; thus, we estimate that the population served in the expansion might have incurred $3.33 million ($972 X 3,430) in Medicaid LTC costs in the first year after their initial screen.

If the expansion—which broadened the population eligible for assessments—was completely effective at eliminating LTC costs, $3.33 million would be the maximum possible savings the program could achieve in one year. Because about 50% of LTC costs are matched with federal funds, the maximum state funds that could have been saved would have been $1.67 million. Since the expansion cost the state general fund $3.45 million, and the estimated maximum amount of savings is $1.67 million, it appears very unlikely that the expansion would have paid for itself, at least in the first year. It is possible, of course, that the full benefits of the expansion might not be observed until subsequent years. Whether longer term savings would be sufficient to offset the expansion costs remains to be tested in a longer-term evaluation.

Research Question 5. What characteristics are associated with increased used of Medicaid LTC?

Because it appears unlikely that the expansion, in its current form, has avoided LTC costs equal to the state investment, future innovations in this program might be focused on those caregiver/receiver pairs most likely to use LTC services. To identify populations are highest risk of LTC costs, we evaluated the total LTC costs in the twelve months following the TCARE screen for all caregivers screened before May 2011. We conducted regression analysis to determine which characteristics are most associated with higher LTC costs in the 12 months after the screen.[12] We observe statistically significantly greater LTC expenditures when the care recipient was already enrolled in Medicaid medical coverage or had been diagnosed with dementia. Likewise, those caregivers with greater numbers of high burdens and those indicating they would consider moving their relative to a residential setting, given the recipient's current condition, on average, had greater LTC costs.

[11] A detailed description of our methods for calculating the estimated cost are provided in the Exhibit A4.1 in the Appendix.

[12] Results of the regression analysis are displayed in Exhibit A5.1 in the Appendix.

CONCLUSIONS AND NEXT STEPS

We report two principal results in this study.

First, based on preliminary data, it appears that the expansion delayed the use of LTC. Because of the very short follow-up period, however, this should be regarded as a tentative finding. The initial recipients of the program will need to be followed over a longer period to determine if this early favorable result persists.

Second, lacking a longer-term evaluation, to answer the legislative question of whether expanding eligibility for the FCSP pays for itself, we adopted an alternative method to estimate the maximum possible savings in the first year after the TCARE screen. We based our estimate on information from a relevant population served before the expansion. Assuming that the expansion was 100% successful at avoiding LTC costs, the maximum possible savings, would have $3.33 million. Further, because half of LTC costs are paid with federal funds, the maximum possible state savings in the first year would have been $1.67 million. Therefore, since the FCSP expansion $3.45 million and our estimate of the maximum state savings is $1.67 million in the first year, it appears unlikely that the expansion would pay for itself, as assumed in the budget.

NEXT STEPS

We observed that the percentage of care receivers using Medicaid LTC increases steadily in the first 30 months following the TCARE screen (see Exhibit 2). For this study, the median follow-up period for the expansion period was 5 months—not enough time to observe any major trend in the use of LTC. To know with greater certainty whether the FCSP expansion delayed or avoided the use of Medicaid LTC, we recommend reanalyzing results of the expansion using a longer follow-up period, at a minimum 12 months. Such a re-analysis could be completed in the upcoming year.

If the state wishes to reduce or delay Medicaid LTC costs by increasing funding for the FCSP, it might consider providing the more in-depth services and supports to those caregivers associated with the greatest LTC costs. Based on information available for the pre-expansion period, those most likely to use LTC are those:

- Whose care receiver is enrolled in Medicaid medical coverage at the time of the screen;
- Whose care receiver has been diagnosed with dementia;
- Who indicate they definitely would consider placing their care receiver; and
- Whose screen responses indicate a greater number of high burdens.

It is also possible that another priority group would be those who are functionally and financially eligible for LTC at the time of the screen. This information was not available for those served prior to the expansion.

The FSCP data system does not track services or expenditures provided for individual caregivers. This lack of information meant that we were unable to address questions regarding whether specific services may have affected use of Medicaid LTC. If the FCSP wishes to monitor which services and supports are most effective in delaying the use of LTC, it would be helpful to record information on services provided to individual caregivers in the TCARE database.

A statement from the DSHS Aging and Disability Services Administration regarding this study is provided in Exhibit A6 in the Appendix.

ACKNOWLEDGEMENTS

I want to thank Jim Mayfield, formerly an Institute Senior Research Associate. He laid out the basic approach for this study, prepared the preliminary report (published in February 2012), and provided helpful advice about analysis as we refined our approach.

Staff at the Family Caregiver Support Program (FCSP) at the DSHS Aging and Adult Services Administration met with us frequently to discuss possible approaches to this analysis. They also provided in-depth information on FCSP, TCARE and the TCARE database, and FCSP expenditure data. I am especially grateful to Hilari Hauptmann, Susan Engels, Lynne Court, Chelsea Buchanan, Leigh Wellcome, James Kettel, Sergio Palma and Xingguo Zhang.

David Mancuso at DSHS Research and Data Analysis Division provided information on Medicaid medical and LTC expenditures, and Department of Health death records matched to care receivers in the TCARE data base. I am grateful, also, for helpful conversations and advice about the analysis.

APPENDIX

A1. Data Sources. The primary source of information for this study was the FCSP TCARE data base. Caregiver responses to the TCARE screens and assessments are recorded in this database. Staff at the DSHS Research and Data Analysis Division matched the records for the care recipients in TCARE to two additional sources:

- Medicaid payment records. These records provided information on the Medicaid LTC payments made each month on behalf of the care recipients and information on whether the care recipient was enrolled in the Medicaid medical program.
- Washington State Department of Health death records.

While considerably more information about the caregiver and the care recipient was available in the assessments, for our regression analysis we limited ourselves to information in the screens. We chose to do this because all caregivers received a screen whereas only a portion of caregivers in the sample had received an assessment.

A2. Identifying screens and assessments. The FCSP direction for the expansion was to serve caregivers not previously in the TCARE system. Thus, all our analyses focused on those caregivers receiving their first TCARE screen. A small number (2%) of caregivers care for more than one care receiver. The caregiver-receiver dyads are treated separately in TCARE and this analysis.

After identifying the first TCARE screen, we identify the first assessment occurring with 45 days of the first screen. Under the guidelines established by FCSP, an assessment should occur within 30 days of the screen or a second screen must be administered. However, there seem to be exceptions to that policy. In order to identify as many assessments as possible, we include assessments that occur with 45 days of the initial screen.

A3. Effect of expansion on time to use of LTC. For this analysis we used Cox regression, a type of survival analysis that allows comparison of outcomes for populations with varying follow-up periods. The p-values for the expansion is <0.0001, indicating the effect is highly significant. We are cautious about these findings because the maximum follow-up period for the expansion was only 10 months, while that for the pre-expansion group was 36 months. Nonetheless, until the study's timeframe can be extended, the finding indicates a favorable outcome for reduced use of LTC.

Exhibit A3.1.
Effect of Expansion on Time to Use of Medicaid LTC

Number of Care Recipients	6,001

Analysis of Maximum Likelihood Estimates					
Parameter	**Parameter Estimate**	**Standard Error**	**Chi-Square**	**P-value**	**Hazard Ratio**
Expansion	-0.38544	0.11279	11.6774	0.0006	0.68
Number of high burdens	0.1103	0.0249	19.6271	<.0001	1.117
Medicaid medical	1.68012	0.09624	304.7818	<.0001	5.366
Diagnosed dementia	0.11452	0.09191	1.5523	0.2128	1.121
Would consider residential placement	0.5906	0.13444	19.2991	<.0001	1.805
Caregiver is spouse (compared to not spouse)	-0.04366	0.08891	0.2411	0.6234	0.957

A4. Estimating potential LTC costs/savings for the expansion population. For this analysis, we used the sample of caregivers with screens before May 2011 (in the pre-expansion period) who did not receive an assessment. Because we find that the use of LTC varies with the number of high burdens indicated by the caregiver, we stratified the sample into six groups, based on the number of high burdens. For each level of high burdens, we ran a regression where the dependent variable was Medicaid LTC costs in the 12 months following the screen. This allows us to identify the relationship between caregiver/receiver characteristics and LTC costs. Then we used the profile of those served in the expansion population to calculate the average LTC costs for the expansion population for each high burden grouping. Finally, we calculate total estimated LTC cost for the expansion, weighting by the number in the expansion. The results of the regressions and cost estimates are provided in Exhibit A4.1.

For example, in the pre-expansion period, of those without assessments who had 0 high burdens, if the caregiver was the spouse – compared to all other caregiver/receiver relationships—LTC costs in the next 12 months was reduced by $732.83, relative to the intercept.

For each high burden group we estimate what the average cost in the expansion would have been without assessments, using percentages observed in the expansion population, by the following equation:

> Average 12-month cost=intercept+(coeff spouse X percent spouse)+(coeff Medicaid medical X percent Medicaid medical) + (coeff Dementia X percent Dementia) +(coeff consider moving X percent consider moving).

We then take the average cost of the six groups, weighting by the number of caregivers in the expansion in each group. We estimate that the average 12-month LTC group would have been $972 if the caregiver did not receive an assessment. We estimate that the total federal and state LTC costs for the expansion group would have been $3,332,892 ($972 X 3,430 caregivers screened during the expansion.)

Exhibit A4.1
Estimating Medicaid LTC Costs for Those Served by the Expansion Assuming They Did Not Receive an Assessment

	Ordinary Least Square Regression Results Pre-Expansion Caregivers without Assessments			Caregivers in Expansion		
Number of High Burdens	**Variable**	**Intercept**	**Coefficient**	**N**	**Percent in Expansion Population**	**Est. Ave cost**
0	Spouse	943.38	-732.83	671	38.7%	$831.49
	Medicaid medical		426.87		21.0%	
	Diagnosed Dementia		188.94		28.8%	
	Definitely consider moving		989.58		2.8%	
1	Spouse	564.89	-575.01	609	47.8%	$973.98
	Medicaid medical		2843.03		11.7%	
	Diagnosed Dementia		-25.39		34.8%	
	Definitely consider moving		6666.54		5.4%	
2	Spouse	70.16	18.63	524	44.5%	$1,067.44
	Medicaid medical		4337.27		11.5%	
	Diagnosed Dementia		593.29		36.8%	
	Definitely consider moving		3679.32		7.4%	
3	Spouse	-442.38	1408.47	557	47.9%	$945.13
	Medicaid medical		5053.41		10.8%	
	Diagnosed Dementia		-612.07		37.0%	
	Definitely consider moving		6101.89		6.5%	
4	Spouse	59.35	-286.66	580	46.6%	$565.63
	Medicaid medical		3613.97		11.2%	
	Diagnosed Dementia		387.55		35.9%	
	Definitely consider moving		941.09		10.2%	
5	Spouse	-932.06	3571.40	489	47.2%	$1,570.48
	Medicaid medical		5642.13		11.0%	
	Diagnosed Dementia		-290.50		38.2%	
	Definitely consider moving		2432.77		12.5%	
All	Average 12-month LTC costs for entire expansion			3,430		$971.69

A5. Identifying characteristics associated with higher Medicaid LTC costs. For this analysis, we use records for all caregivers screened before May 2011, allowing a full 12-month follow-up for all care receivers. Characteristics with statistically significant impacts on LTC costs include greater number of high burdens, being enrolled in Medicaid medical coverage at screen, a diagnosis of dementia, and the caregiver's willingness to consider moving the care receiver to a residential setting.

Exhibit A5.1
Regression Results Estimating Medicaid LTC Costs
In the 12 Months After the TCARE screen

Number of care recipients	3,037	
Parameter Estimates		
Variable	**Estimate**	**P-value**
Intercept	-17.75	0.9228
Number of high burdens	140.08	0.0030
Medicaid medical at screen	3027.00	<.0001
Diagnosed dementia	349.39	0.0414
Would consider residential placement	2118.49	<.0001
Caregiver is spouse (compared to not spouse)	229.16	0.1734

Exhibit A6
Statement from the DSHS Aging and Disability Services Administration

STATE OF WASHINGTON
DEPARTMENT OF SOCIAL AND HEALTH SERVICES
AGING AND DISABILITY SERVICES ADMINISTRATION
*PO Box 45600 * Olympia, WA 98504-5600*

November 21, 2012

Marna Miller
WA State Institute for Public Policy
P.O. Box 40999
Olympia, WA 98504

Dear Marna Miller:

Thank you for the time, dedication and energy you provided on the WSIPP report related to the Family Caregiver Support Program (FCSP) expansion. We appreciate the legislators' interest in understanding the fiscal impacts of their investment in expanding access and services to unpaid family caregivers. As recognized in the report, WSIPP was charged with a specific focus of measuring the Medicaid LTC cost savings achieved by providing expanded FCSP services to family caregivers new to the program. At the outset there were challenges to the study including lack of a control group and not having enough time to measure the full outcome of the expansion.

As the study suggests, based upon preliminary data, the FCSP expansion appears to delay the use of long term care (LTC) Medicaid Services at a statistically significant level. The state has made important investments in supporting unpaid family caregivers since 1989. We recognize the intent of this study was focused primarily on the outcomes of the care receiver in the Medicaid long term care system, and therefore did not expect to see addressed outcomes experienced by the caregivers served. However, in isolating this one outcome measure, some of the critical benefits of FCSP itself may be overlooked, such as improving depression and stress for caregivers, which can lead to improved health and lower health costs for the caregiver. A significant number of caregivers (45%) rate their health from fair to very poor. The FCSP emphasis on wellness is critical for so many of the caregivers. Additional information and fact sheets about the FCSP can be found at http://www.adsa.dshs.wa.gov/professional/TCARE/.

It is important to note, the target population also in need of further study is the caregivers who were supported through the evidence based caregiver assessment (TCARE®- Tailored Caregiver Assessment and Referral) in FY 2012. The use of TCARE® offers a consistent, customized consultative process allowing caregivers to make informed choices based on an algorithm driven, online system, and receive tailored services and resources to addresses their individual caregiver risks and needs. The WA State legislature required that ADSA adopt an evidence based caregiver assessment in 2007. ADSA and its Area Agency on Aging (AAA) partners have invested tremendous resources in advancing this process statewide over the past three years. As published in a national peer review journal, the efficacy of the protocol in benefitting caregivers is not in

question, and the individuals receiving the full TCARE® protocol were the focus of the FCSP expansion. We know from data contained in TCARE that family caregivers who access the FCSP are a vulnerable group in their own right.

From ADSA's TCARE® database of the family caregivers who received a TCARE® assessment in FY 12's FCSP expansion, we know:

- **40%** of their family members/care receivers report that they had financial resources that would make them eligible for Medicaid LTC Services ($2,000 if single, or $50,000 if married).
- Another **32%** of the care receivers had financial resources available to them to cover up to 6 to 9 months of long term care expenses (including private pay nursing home costs).

The population of individuals age 65 and over in Washington State will double in the next twenty years emphasizing the need to invest in evidence based and cost effective programs that divert individuals from more costly Medicaid LTC services. ADSA and stakeholders are concerned that the challenges presented to this study greatly impact the finding around fiscal efficacy. ADSA is committed to strategic program refinement to effectively serve the growing family caregiver population in WA State. We welcome the opportunity to work towards a further FCSP study using alternative approaches to capture the vital information on the caregivers and care receivers served to inform legislative decision makers. Thank you again for all your efforts and for the opportunity to comment on this report.

Sincerely,

Bea Rector

Bea Rector, Interim Director
Home and Community Services

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

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