

C-2 HEALTH PROMOTION, DISEASE PREVENTION, & DELAY OF MEDICAID-FUNDED LONG TERM SERVICES & SUPPORTS

C-2a. Family Caregiver Support Program (FCSP)

In recent years, much attention has been placed nationally on the plight of the unpaid family caregiver. Surveys have been conducted by such entities as AARP, the National Alliance for Caregiving, Mass Mutual, and Easter Seals. These surveys have shown that family caregivers are taking on tasks that are more complex, intensive, and even medical or nursing in nature.

Often caregivers are thrust into the role without any training in the basics, let alone the more medically complex tasks. Caregivers are faced having to choose between caregiving and employment, reducing their current incomes and that of their future retirement.

Their financial health is not the only kind to suffer. Family caregivers are far more likely to neglect their own health rather than that of their care recipients. The 24/7 nature of their work leaves them little time for self care. As Baby Boomers age, more and more care will be required from informal sources if they are to age in place.

In Washington State, family caregivers have long been recognized as the backbone of the long term care system. Family Caregiver Support Program services are administered by Area Agencies on Aging (AAA) to provide information, referral, assistance, and case management to help these caregivers take care of themselves while providing care to family and friends. While supporting

these caregivers is the primary goal of FCSP, a secondary one is financial. When care receivers are enabled to safely remain in their homes longer, everybody benefits. FCSP provides the help a family caregiver may need in prevent or delay placement in more costly environments. Moving to skilled nursing facilities and other out-of-home placement settings often drains a family's resources. When these resources are exhausted, the cost of care falls to the state. The successful implementation of FCSP services has been shown to slow the transition to Medicaid-funded long-term care.

Challenges in the Family Caregiver Support Program – Problem Statement

The following are some of the challenges and barriers to serving family caregivers:

- Family caregivers do not identify themselves as caregivers and therefore do not seek out caregiver services.
- Family caregivers are often reluctant to accept help for a number of personal and cultural reasons.
- Minorities often have cultural norms and family expectations that make it difficult to reach out for and/or accept help.
- There can be a fear of government rules, regulations, and intrusions. Privacy concerns can be a barrier to seeking help.
- Offering services in rural areas is complicated by distance to/from services and the lack of available vendors or contractors of services.
- Adult day care programs are available in only four of ALTC's eight counties.
- The term "Adult Day Care" can have

negative connotations, impacting a willingness to use it.

- The lack of innovative programs providing relief for caregivers at night.
- The lack of awareness of the programs available to help family caregivers.
- The conservative political climate of Eastern Washington can have an impact on service to LGBT and other non-traditional family units.

The adoption of TCARE has increased the efficacy of FCSP

TCARE stands for Tailored Caregiver Assessment and Referral. This evidence-based tool was adopted by the Washington State Legislature in 2009 to provide consistency across the state in family caregiver programs and services. Since its inception in 2000, the Family Caregiver Support Program has looked very different in each AAA.

An FCSP service offered in one AAA may not be available in another. So while TCARE helps to provide consistency across the state, AAAs are given the flexibility to customize program offerings to fit budget and resource constraints.

ALTC offers the following services to caregivers:

- TCARE screening. Available in all 8 counties, TCARE screeners begin the dialog with caregivers, helping them to see themselves as caregivers and to begin to recognize that, while the caregiver experience is unique for everyone, caregivers do share some commonalities. For most caregivers, additional stress is now

part of their lives and for some, the many stressors are overwhelming.

- TCARE assessment. Available in all 8 counties, the assessment provides the best way for the family caregiver specialist to have a more complete understanding of the caregiver’s situation and circumstances and is an efficient way to determine which goals a caregiver might need to address in order to reduce stress and burden. Once a goal is identified, strategies to meet that goal can be discussed with the caregiver and services to support those strategies can be selected.
- Respite in-home personal care. Agency care providers assist care receivers with personal care and light housekeeping tasks, enabling family caregivers to attend to their own health, other personal needs, or to simply take time for themselves. Eligibility restrictions and a sliding scale fee apply. Available in all 8 counties.
- Adult Day Services. Adult Day Care programs are designed to provide care and companionship for seniors who need assistance or supervision during the day. Adult Day Health programs offer supervised daytime activities with skilled nursing and rehabilitative therapy services available for those care receivers with more complex medical needs. As with in-home respite, there are eligibility restrictions and a sliding scale fee applies. Adult Day Care programs are available in Yakima,

Benton/Franklin, and Walla Walla counties. Adult Day Health is available only in Benton/Franklin.

- Short term respite. This provides in-home personal care to the care receiver by trained agency professionals while the caregiver is attending conferences, educational offerings and trainings. Available in all 8 counties.
- Housekeeping and Errands is a supplemental service that assists caregivers with the upkeep of the care receiver’s home and with those errands the caregiver cannot attend to due to caregiving responsibilities. There is no cost to the caregiver or care receiver for this service. Eligibility restrictions do apply. Available in all 8 counties.
- Counseling to help with coping skills, communication, stress reduction, understanding the disease process, planning for the future and family mediation. This is short term and solution focused. Available in all 8 counties.
- One-on-one consultations with family caregiver specialists. TCARE screeners and assessors hold individual sessions with caregivers to discuss community resources, web-based information sources, and to help caregivers find answers to difficult questions and situations. Available in all 8 counties.
- Powerful Tools for Caregivers. This evidence-based, 6-week course is

designed to help family caregivers develop and practice self-care “tools” and to thrive as individuals while managing caregiving responsibilities. Weekly topics include:

- Taking care of you
- Identifying and reducing personal stress
- Communicating feelings, needs, and concerns
- Communicating in challenging situations
- Learning from our emotions
- Mastering caregiving decisions

There is no charge to the caregiver for this class. Classes are offered in Ellensburg, Yakima, the Tri-Cities, Walla Walla, and the Clarkston area.

- Free in-home caregiver training by ALTC RNs. These RNs offer instruction on basic nutrition, skin care, medication management and safety techniques. This essentially offers the family caregiver some of the information and training they would receive at a Fundamentals of Caregiving class for paid providers, but in their home environment on a one-on-one basis. Available in all 8 counties.
- Support groups. Caregivers learning from one another and sharing with each other are valuable sources of support. ALTC sponsors support groups in Kittitas and Walla Walla counties. New groups are forming in Columbia and Asotin counties. Referrals are made to existing support groups not sponsored by

ALTC in Yakima, Benton and Franklin counties. Garfield county caregivers are encouraged to attend the support group in either Columbia or Asotin County or to take advantage of online support groups and chat rooms.

- Supplemental Services include:
 - Free home safety evaluations to identify potential equipment or environmental modifications that will assist the caregiver to safely provide care. Available in all 8 counties.
 - Assistance with the purchase of durable medical equipment. If the care receiver does not have insurance coverage that will purchase DMEs, FCSP may purchase the items recommended by the home safety evaluation up to \$250. Available in all 8 counties.
 - Environmental modifications to help adapt a home to the needs of the care receiver. These might include the installation of bathroom safety equipment like grab bars and raised toilet seats, ramps, and widening of doorways. Available in all 8 counties.

- A lending library that includes books, videos and DVDs is available in all 8 counties.

- Referrals to chronic disease self management programs. Many

caregivers have their own chronic diseases to deal with as well as those of their care receivers. Referrals can be made for both the caregiver and care receiver to this evidence-based program.

- Referrals to the Senior Center Dental Hygienist program. Referrals to this program can help both the senior caregiver and the senior care receiver.

- Referrals to community based resources and programs. Our TCARE screeners and assessors work in ADRC offices and, as such, are uniquely situated to provide information, assistance, and referrals.

Strategies for Continued Development or Expansion of FCSP Using Current and Potential Expansion Funding

Funding is always an issue. With increased funding, more caregivers could be helped sooner in their caregiver journey. But funding does not appear to be increasing at this point.

ALTC houses its FCSP services within the ADRC offices. This is cost effective as ADRC staff is familiar with local resources and can make referrals, provide assistance, and case management to family caregivers as a part of their ADRC duties.

At present, ALTC has had to reduce hours for ongoing services such as In-Home Respite and Housekeeping and Errands. This has enabled us to offer these vital programs to more caregivers. Should funding increase, we could increase hours

and also serve more caregivers. Should funding substantially increase, it is hoped that ALTC's high thresholds for qualifying for ongoing services could be lowered to match those of most of the AAAs in Washington.

ALTC utilizes 1/3 sheet FCSP brochures that contain information about how caregiver specialists will work with caregivers to develop a plan to reduce stresses and burdens. Separate brochures for each of the eight counties are available in English and Spanish. These are disseminated at health fairs, in doctor's offices, at educational conferences, and are available to Home and Community Services to be included in Medicaid long term care application packets. Care transition coaches have these available for the hospitals with whom they are working. These are disseminated to various kinds of support groups as well.

Powerful Tools for Caregivers brochures are also available. Specific brochures for each county contain local office contact information.

One strategy used during the 2011 and 2012 FCSP expansion was for the FCSP Coordinator to work intensively with TCARE Screener staff in each office to increase the number of TCARE screens. This proved to be extremely effective, resulting in ALTC meeting their target numbers early in the project. This strategy continues to be used to increase the number of family caregivers served throughout our region. In addition, the FCSP Coordinator will be working with all ADRC staff with the goal of enhancing customer service for all programs and ensuring cross referrals.

While National FCSP funds can only be used to serve caregivers of seniors at least 60 years old or who have dementia, State FCSP funds can be used to support caregivers who assist adults who do not meet these criteria. Older individuals caring for people with severe disabilities, including developmental disabilities, can be assisted as well.

Strategies to address Alzheimer's and Dementia

In 2015, the National Alliance for Caregiving and AARP released the results of a nationwide survey of caregivers showing that 22% of the 43.5 million caregivers responding were caring for someone with some form of dementia. That works out to over 9.5 million caregivers. The number of people suffering from Alzheimer's and/or other dementias is only going to increase as more and more Baby Boomers become seniors.

Washington State is crafting an Alzheimer's State Plan. The Alzheimer's Association Washington Chapter is spearheading this effort, in conjunction with AL TSA, and has been gathering input from communities around the state. This chapter has been formed by the merging of the Western and Central Chapter with the Inland Northwest Chapter. In the past, ALTC has had 2 counties served by one chapter and 6 counties served by the other. The merger will make coordination of effort more seamless. Regional Councils have been set up. The FCSP Coordinator is a member of the Regional Council that meets quarterly in Yakima.

ALTC has increased the number of services offered to caregivers who are dealing with

dementia. In addition to TCARE assessments that help to identify goals and strategies for these caregivers, ALTC also offers enhanced dementia options counseling in every ADRC office. ALTC staff makes referrals to the Alzheimer's Association and their support groups in our area. We also offer a lending library of books and DVDs, including ones featuring Teepa Snow, the renowned Occupational Therapist and expert on dementia.

ALTC offers two evidence-based, in-home coaching programs that help caregivers working with dementia care receivers, STAR-C2 and RDAD.

STAR-C2 Program

The STAR-C2 intervention developed by the University of Washington is currently offered in Yakima, Asotin, Garfield, and Kittitas counties. ALTC has two staff trained in this protocol and plan to send a minimum of four more staff to the next available STAR-C2 training in late September of 2015. STAR-C2 is an evidence-based program designed to teach family caregivers to use behavioral strategies to reduce affective disturbances in persons with dementia. It is a behavioral intervention to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers.

Reducing Disability in Alzheimer's Disease (RDAD)

ALTC also has two certified RDAD coaches. RDAD is another evidence-based protocol developed by the University of Washington. It involves training family caregivers to increase exercise for the care receiver. This protocol has been shown to decrease symptoms of depression in care

receivers and in their caregivers as well. This program is offered in Benton, Franklin, Kittitas, and Yakima counties.

Having trained STAR-C2 and RDAD consultants is enabling SE/ALTC to pursue our goal of providing coaches who can work one-on-one with caregivers in their own homes to reduce stress, depression and burnout.

Additional Evidence-Based Programs

Powerful Tools for Caregivers Classes

This 6-week series mentioned above is another evidence-based program offered to caregivers.

Care Transitions Intervention (CTI) and Bridges

ALTC uses CTI and Bridges coaches to work with hospitalized patients identified by hospital staff as being at risk for readmission. The CTI or Bridges coach assists them before discharge to connect with services and supports and works with care receivers to become advocates for themselves when they return home. These programs dovetail well with FCSP. The patients often have informal caregivers. Involving the caregiver in the transition process and supporting that caregiver with FCSP services can only increase the likelihood of more positive outcomes. In some offices Certified TCARE case managers are CTI or Bridges coaches. In other offices, CTI and Bridges coaches make referrals to FCSP.

These evidence-based interventions also meet the criteria for Title III-D as they are health promotion strategies.

Strategies for Quality Assurance and Identifying Caregiver Outcomes

ALTC has an office structure that includes a Local Program Coordinator (LPC) over each office. The Benton/Franklin and Yakima offices, our two largest, also have ADRC Lead Case Managers (LCM). LPCs and LCMs are tasked with reviewing the work of TCARE screeners and assessors to ensure quality interactions with caregivers. Rescreening occurs every six months with full assessments for qualifying caregivers annually. Care plan outcomes are examined at the 6-month and annual marks and changes in the care plan are made to address new stressors. Those services that are showing a reduction in stress and burdens are continued, those that have been shown to be of little or no affect are discussed with the caregiver to see if a change or augmentation is needed.

Satisfaction surveys are conducted with durable medical equipment vendors and environmental modification contractors. Caregivers are randomly selected and called by ALTC Admin staff using a four-question survey to ascertain caregiver satisfaction with the vendors and/or the work or service. Powerful Tools for Caregivers class leaders are required to submit to the FCSP Coordinator the class evaluations at the end of the 6-week session. Random selections of support group attendees are also contacted for their input regarding the leaders who are contracted with ALTC for support group facilitation.

GOAL: ALTC will increase the number of caregivers served by five percent yearly

OBJECTIVES:

- Statistics on the number of new

caregivers assisted will be given to each office quarterly, comparing them to the previous year's numbers.

Ongoing

- In-service trainings will scheduled at least once a year at each office, more often as needed for offices that may be struggling to meet the goal.

Ongoing

GOAL: ALTC will work to train and maintain adequate staffing levels to ensure FCSP services are available to the communities served by each office.

OBJECTIVES:

- FCSP Coordinator will advocate with ALTA for flexibility regarding TCARE Assessor and Screener training to reflect the needs of rural communities experiencing frequent turnover. ***Ongoing***
- Each ALTC office will have a minimum of one trained TCARE Screener located in the office. ***Ongoing***
- There will be two or more certified TCARE Assessors available to each county for conducting assessments. ***Ongoing***
- A minimum of four more ALTC staff will be trained as STAR-C consultants. This will enable Walla Walla, Columbia, Benton, and Franklin county office to offer STAR-C. ***By the end of September 2015***

GOAL: Dementia caregivers will have opportunities for education and support throughout.

OBJECTIVES:

- ALTC will explore possibilities for bringing Early Stage Memory Loss work groups to Walla Walla and Columbia counties. *Ongoing*
- When dementia caregivers are identified, enhanced options counseling will be offered to them. *Ongoing*
- As a member of a Regional Council of the Alzheimer's Association Washington Chapter, the FCSP Coordinator will advocate for increased educational opportunities and support groups available in underserved rural areas. *Ongoing*