

FAMILY CAREGIVING

Profile of the issue:

Family members and other informal caregivers are the backbone of our long-term care system, providing unpaid assistance at home to loved-ones with chronic illnesses or disabilities. It is estimated family members or friends provide 78% of all home care. In Washington State, the number of caregivers in 2004 was calculated to be over 616,000, providing 660 million hours of caregiving per year. The annual market value of those services was estimated to be 6.5 billion dollars.¹

Although family caregiving is not often acknowledged in our society, it is very prevalent. More than one quarter (26.6%) of the adult population has provided care for a chronically ill, disabled or aged family member or friend during the past year. Based on current census data, this translates into more than 54 million people.

Traditionally, women provided the vast majority of care for family members. Now, men make up 44% of the caregiving population. A spouse is most frequently the care provider and in the absence of a spouse, a daughter is most likely to assume the role. In the absence of offspring, more distant family members and friends often take responsibility.

Many caregivers of older people are themselves elderly. Of those caring for someone aged 65+, the average age of caregivers is 63 years, with one third of these caregivers in fair to poor health.

The aging of our population and changing patterns of family life intensifies demands on family caregivers, while the pool of caregivers is dwindling. In 1990, there were 11 potential caregivers for each person needing care. By 2050, that ratio is estimated to shrink to four caregivers for each person needing care.

Whenever possible, family caregivers prefer to care for their loved-ones at home and often at great personal sacrifice. The caregiver role can result in enormous emotional, physical, and financial hardships. Worries over paying for care especially plague middle income families who are not eligible for public benefits, yet cannot afford the out-of-pocket costs of care. At least half of family caregivers juggle work, family, and caregiving responsibilities. As a result of their caregiving, informal caregivers are estimated to each lose an average of \$25,494 in Social Security benefits, an average of \$67,202 in pension benefits and an average of \$566,433 in wage wealth. Combined, the result is a loss of \$659,139 over a lifetime. Nationally, work disruptions due to caregiving cost businesses an estimated \$11.4 to \$29 billion annually.

¹ Nat'l Family Caregivers Assn. & Family Caregiver Alliance (2006), *Prevalence, Hours and Economic Value of Family Caregiving*, Peter Arno, PhD.

Caregiving is a dynamic process that unfolds over time. The types and intensity of tasks family caregivers perform vary dramatically, depending on the familial role of the family caregiver. Spouses report performing between 40 to 60 hours of caregiving tasks that may include household chores, meal preparation and personal care, (bathing, dressing and toileting). In contrast, adult children, on average, spend 15 to 30 hours per week performing care tasks which are provided in shorter periods of time and tend to concentrate more on care management and assisting with transportation, banking, and shopping.

Family caregivers, especially spouses, seek formal assistance relatively late in their caregiving career. Whether or not a family caregiver will choose to accept a service is dependent on many factors including whether or not a service will be of assistance in their situation or for their condition. For example, if the wife of an impaired older man adheres to the belief she is responsible for her husband's care, she may well experience serious guilt or embarrassment if she seeks the help of an outsider. On the other hand, as the wife's health condition deteriorates or as the burden of care increases, due to the increasing demands of caregiving or the perceived loss of a significant relationship, the benefits associated with outside assistance will increase.

Because family caregivers arrive at their new role with very diverse histories, they also arrive with very different support needs. Consequently, some family caregivers simply need information, other caregivers need emotional support, and still others need direct assistance with care tasks. When they do seek help, caregivers use services such as education programs, in-home respite care, adult day services, counseling, family consultations, support groups and home health care.

Family Caregiver Programs Serving Snohomish County provides a network of services that includes:

- A Family Caregiver Resource Line
- A Family Caregiver Website
- Educational workshops
- Caregiver trainings, including "Taking Care of You, Powerful Tools for Caregiving" and "Chronic Disease Self Management"
- Five Caregiver Resource Centers, with two serving rural Snohomish County in the north and east, and each center hosting a variety of services including a caregiver library
- Caregiver Kits
- Caregiver Support Groups
- Expanded Respite and Adult Day Care services
- Ethnic Outreach Project serving the Chinese, Filipino, Korean, Vietnamese, Russian and Hispanic caregiver communities
- Outreach materials and resource directories targeted to specific groups such as communities of faith and businesses

- Collaborations with communities of faith, hospitals, rehabilitation centers, retirement facilities, businesses and other law enforcement entities
- One centralized, countywide, Grandparents Raising Grandchildren (Kinship Care) Program

Interest in family caregiver issues and use of the caregiver support services has grown dramatically since the program's inception. For example, the number of requests for information from the Family Caregiver Resource Line increased from 1,471 (2001), to 2,100 (2006). The Caregiver Website, www.snocare.org, was accessed by 2,295 unduplicated individuals in 2001. By 2006, the number had grown to 10,500 unduplicated people visiting the site for information.

Our family caregiver efforts have and will continue to focus on addressing the needs of the developmental disabilities population and individuals who do not self-identify as caregivers. We work with Senior Services of Snohomish County and the Snohomish County Division of Developmental Disabilities and have created joint marketing efforts to target the caregivers of individuals with DD. Our general marketing approach has been to focus on disease specific marketing, thus reaching people who do not self-identify as caregivers.

As the Family Caregiver Programs in Snohomish County have developed, there has been increased interaction with the Alzheimer's Assn. of Western Washington. In 2007, a special project between LTCA and the Alzheimer's Assn. provided training to each of 900+ sworn officers in Snohomish County recruited for this training. This training, entitled "Alzheimer's/Dementia Recognition Training", was formulated to help officers recognize dementia and be familiar with resources to assist individuals and families in accessing appropriate interventions.

Supporting individuals as caregivers enables them to continue in that role for an extended period of time, and their loved-ones can remain at home for a longer time. Receiving long term care services in one's home instead of an institutional setting not only is the choice of most people, it results in huge savings to the public. In 2008, the average monthly cost (in Washington State) per case for nursing homes was \$3,831, while the average monthly cost per case for community services was \$1,423.

Problem/Need Statement:

During the past few years, there has been a growing recognition of the contributions and challenges faced by family members and other informal caregivers. Public policy (and with it the availability of new public funds) has been directed toward developing services supporting these caregivers. In Snohomish County, a network of services has been developed to support family caregivers and help sustain them in their caregiving role. This network is called "Family Caregiver Programs Serving Snohomish County."

There is a continued need for ensuring the community knows about the availability of services. In addition, services need to be expanded and refined to meet the needs of caregivers throughout the county. As our county's population continues to grow in diversity, further efforts to ensure family caregiver services are accessible and culturally appropriate will need to be made.

Goal: Increase resources and services for family caregivers in Snohomish County.

Objective: Expand and strengthen the capacity of the Family Caregiver Network.

Measurable Activity: Upgrade and redesign the Family Caregiver Website – www.snocare.org March, 2008.

Measurable Activity: Expand the Kinship Caregiver Support Program (KCSP) by recruiting 10 new community advocates in County school districts and serving 65 kin families. December, 2008.

Measurable Activity: All family caregiver staff will be trained as Class Leaders in *Powerful Tools for Caregiving*; all kinship caregiver staff will be trained in *Parenting the Second Time Around*; and all family caregiver staff will receive disease specific education for dementia. Continuing education / training is designed to improve the quality and consistent delivery of Family Caregiver Program services throughout the County. December, 2008.

Objective: Expand resources for targeted populations.

Measurable Activity: Add additional contractors with the capacity to serve targeted populations of caregivers that may include, but not be limited to, individuals: living in rural communities, involved in non-traditional families, older adults caring for disabled adults, families with limited English, and Native Americans. (Note: pending additional funds through the State Family Caregiver Program.) June, 2009

Measurable Activity: Continue to provide caregiver-related educational programs to the ethnic elder community via the annual Ethnic Elder Resource Fair. December, 2008 and ongoing

Measurable Activity: Initiate and develop working relationship with caregivers and kin families who are in non-traditional families. Meetings will be tracked and a count made of participants. December, 2008

Goal: Strengthen the Family Caregiver Network through increased collaboration.

Objective: Develop formal collaborative relationships with programs and services affiliated with the Family Caregiver Program.

Measurable Activity: Develop a multi-year strategic plan with the Alzheimer's Association, Central and Western Washington Chapter. March, 2008

Measurable Activity: Develop a formal working relationship between the Family Caregiver Program and community programs to include, but not be limited to: Adult Day Health / Day Care, Respite, Depression Screening Program, Senior Peer Counseling Program, Sunrise Services, and the Alzheimer's Association. March, 2008.

Objective: Develop and/or increase informal collaborative relationships with programs and services affiliated with the Family Caregiver Program.

Measurable Activity: Expand and strengthen relationships with Communities of Faith to include, but not be limited to: training (Alzheimer's / Dementia for Faith Ministry leaders and caregivers); resources for older adults; consultation; and caregiver-related services that can be delivered by faith communities. December, 2008 and 2009.

Measurable Activity: Expand and strengthen the cadre of trained community advocates active with the Kinship Caregiver Support Program. Targeted organizations may include, but not be limited to: the public schools system (via school counselors), the Family Support Centers, DDD, ECEAP, Senior Centers, and community-based not for profit organizations. Goal for 2008 is a total of 50 advocates; for 2009, a total of 75 advocates.

Goal: Expand public awareness of Family Caregiver Programs and their effectiveness.

Objective: Conduct program outreach and marketing.

Measurable Activity: Develop and conduct program outreach and marketing activities to reach targeted communities that may include, but not be limited to: Communities of Faith, non-traditional families, ethnic and Native American caregivers, medical professionals, the court-system, and employers. Ongoing.

Objective: Assess program outcomes for continual improvement.

Measurable Activity: Develop and conduct annual program evaluation. Incorporate findings into overall programming. December, 2009 and 2010.

Goal: Integrate TCARE into our existing family caregiver program.

Objective: Implement our AAA roll-out plan.

Snohomish County delivers services through: Respite services (managed at the County), two countywide service providers (Senior I & A and the Alzheimer's Association), and four community-based organizations, strategically located based on geographic representation and population density. Each site provides a full menu of core services.

Measurable Activity: Establish IT connection to the state by Fall of 2009/Spring of 2010.

Measurable Activity: Secure TCARE training for targeted staff by December, 2009.

Measurable Activity: Develop protocol and strategies for training new TCARE screeners by the Fall of 2009.

Measurable Activity: Develop a TCARE phase-in service strategy by Fall of 2009.

Goal: Refine the newly created centralized, countywide community-focused kinship caregiver support program in Snohomish County.

Objective: Monitor and evaluate the service model for the Kinship Caregiver Program

Measurable Activity: Conduct a formal assessment of the program. 1st quarter, 2010.