



Benefits and Cost-Savings Due to Respite

Family Caregivers Save the Government Billions of Dollars—Respite Saves the Caregivers

- In 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion in 2009, up from an estimated \$375 billion in 2007. This amount (\$450 billion) is more than total Medicaid spending in 2009, including both federal and state contributions for both health care and LTSS (\$361 billion), and as much as the total sales of the world's largest companies, including Wal-Mart (\$408 billion in 2009, the most of any company) and the three largest publicly held auto companies combined (Toyota, Ford, Daimler: total \$439 billion). Including caregiving for children with special needs in the total would add 4 to 8 million additional caregivers and another \$50 to \$100 billion to the economic value of family caregiving (Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving, AARP Public Policy Institute, 2011).
- Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization (Mandell, David S., et al, 2012).
- Family caregivers may suffer from physical, emotional, and financial problems that impede their ability to give care now and support their own care needs in the future. Without attention to their needs, their ability to continue providing care may be jeopardized.
- Respite care is one of the services that Alzheimer's caregivers say they need most. One study found that if respite care delays institutionalization of a person with Alzheimer's disease by as little as a month, \$1.12 billion is saved annually (Leon, et al., 1998). A similar study in 1995 found that as respite use increased, the probability of nursing home placement decreased significantly (Kosloski, K. and Montgomery, R.J.V., 1995).
- The average costs for certain agencies/individuals to provide planned respite are about \$10-\$12 per hour, less costly than placing children in out-of-home care. The national average (non-specialized) foster care maintenance payment is \$4,832 per year and the average monthly cost of foster care for children up to age 16 with special needs is \$11,651 per year, while it is estimated that providing 12 hours of respite each month costs \$1,422.88 per year (ARCH and Child Welfare League of America, Planned and Crisis Respite for Families with Children: Results of a Collaborative Study, 2002).

- For the majority of individuals in the care of a family caregiver, for example someone who may require hands-on non-medical assistance, the median hourly rate for a licensed homemaker or home health aide is \$18/\$19. Also, the national median daily rate for adult day care is \$60. If these services are used periodically as respite, for example at a therapeutic rate of 8 hours of respite per week, the cost would still be far less than full time assisted living or nursing home care (\$592 per month for licensed homemaker or home health aide or \$240 per month for adult day care). The national median rate for assisted living is \$3,185 per month, while the national median daily rate for nursing home care in a semi-private room is \$185/day or \$5735 per month (Genworth Financial, 2010 Cost of Care Survey, April 2010).
- In the Oklahoma Lifespan Respite Program, where all family caregivers are provided \$200-\$400 every three months in respite vouchers, the family caregiver negotiates rates of \$5.62 to \$5.92 per hour with providers, much less than the Oklahoma agency costs ranging from \$12.80 to \$18.00 per hour. Nearly 100% (98.2%) of the caregivers served in the voucher program are very satisfied, not just because the funds are available, but because they are allowed to hire someone they trust and to control the amount a provider is paid. The caregiver is recognized as the expert trainer and the person who knows what is best for their loved one (Percival, Oklahoma Respite Resource Network, 2005).
- U.S. businesses also incur high costs in terms of decreased productivity by stressed working caregivers. A study by MetLife estimates the loss to U.S. employers to be between \$17.1 and \$33.6 billion per year. This includes replacement costs for employees who quit because of overwhelming caregiving responsibilities, absenteeism, and workday interruptions. (Metropolitan Life (MetLife) Mature Market Institute, 2006)
- A recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. The study found that six in ten caregivers are workers and during this current economic downturn 50% of them are less comfortable with taking time off from work to care for a family member or friend. A similar percentage (51%) says the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend. (NAC and Evercare, 2009)

Preventing Caregiver Health Problems Can Save Dollars in Reduced Hospitalizations, Doctor Visits, Work Absences

- Significant percentages of family caregivers report physical or mental health problems due to caregiving.
 - ➡ A survey of caregivers of children, adults and the disabled conducted by the National Family Caregivers Association, found that while 70% of the respondents reported finding an inner strength they didn't know they had, 27% reported having more headaches, 24% reported stomach disorders, 41% more back pain, 51% more sleeplessness and 61% reported more depression (National Family Caregivers Association, <http://nfcacares.org/survey.html>, April 30, 2000).
 - ➡ Three fifths of family caregivers age 19-64 surveyed by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared

with only one-third of non-caregivers. Caregivers reported chronic conditions at nearly twice the rate of noncaregivers (45% to 24%).

- A JAMA study found that participants who were providing care for an elderly individual with a disability and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls (Schulz and Beach, December 1999).
- In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Respite for Younger Family Members with Disabilities Improves Family Stability, Reduces Chances of Out-of-Home Placements

- Respite has been shown to improve family functioning, improve satisfaction with life, enhance the capacity to cope with stress, and improve attitudes toward the family member with a disability (Cohen and Warren, 1985). In a 1989 national survey of families of a child with a disability, 74% reported that respite had made a significant difference in their ability to provide care at home; 35% of the respite users indicated that without respite services they would have considered out-of-home-placement for their family member (Knoll, James, Human Services Research Institute, March, 1989)
- There was a statistically significant reduction in somatic complaints by in a study of primary caregivers of children with chronic illnesses, and a decrease in the number of hospitalization days required by children, as a direct result of respite care (Sherman, B.R., 1995).
- Data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and antibiotics use decreased by 71% (Mausner, S., 1995).
- An evaluation of the Iowa Respite Child Care Project for families parenting a child with developmental disabilities found that when respite care is used by the families, there is a statistically significant decrease in foster care placement (Cowen, Perle Slavik, 1996).
- A study of Vermont's 10-year-old respite care program for families with children or adolescents with serious emotional disturbance found that participating families experience fewer out-of-home placements than nonusers and were more optimistic about their future capabilities to take care of their children (Bruns, Eric, November, 15, 1999).

Similar Positive Results Found When Caregivers of the Elderly Use Respite

- Respite for the elderly with chronic disabilities in a study group resulted in fewer hospital admissions for acute medical care than for two other control groups who received no respite care (Chang, J.I., Karuza, J., Katz, P.R, et al, Journal of the American Board of Family Practice, 5: 1992).
- Sixty-four percent of caregivers of the elderly receiving 4 hours of respite per week after one year reported improved physical health, 78% improved their emotional health, and 50% cited improvement in the care recipient as well. Forty percent said they were less likely to institutionalize the care recipient because of respite (Theis, S.L., et al, 1994).
- Caregivers of relatives with dementia who use adult day care experience lower levels of caregiving related stress and better psychological well-being than a control group not using this service. These differences are found in both short-term (3 months) and long-term (12 months) users. (Zarit, S.H. et al, 1998)

Respite Provided Across the Lifespan Yields Positive Outcomes

- In a survey conducted by the Oklahoma Respite Resource Network, 88% of caregivers agreed that respite allowed their loved one to remain at home, 98% of caregivers stated that respite made them a better caregiver, 98% of caregivers said respite increased their ability to provide a less stressful environment, and 79.5% of caregivers said respite contributed to the stability of their marriage. (Testimony of Jan Moss, Senate Finance Committee, April 2004)
- When newly formed, the Nebraska statewide lifespan respite program conducted a statewide survey of a broad array of caregivers who had been receiving respite services, and found that one out of four families with children under 21 reported that they were less likely to place their child in out-of-home care once respite services were available. In addition, 79% of the respondents reported decreased stress and 58% reported decreased isolation (Jackson, Barbara, Munroe-Meyer Institute, University of NE Medical Center, January 2001).
- Data from an outcome based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages (Wade, C., Kirk, R., Edgar, M., & Baker, L. (2003). *Outcome Evaluation: Phase II Results*. Chapel Hill, NC: ARCH National Resource Center for Respite and Crisis Care).

Complete reference available upon request.

Prepared by the National Respite Coalition, Updated January 2012. For more information, please contact Jill Kagan at jbkagan@verizon.net or 703-256-2084.