



Respite Benefits and Cost-Savings

Family Caregivers Save the Government Billions of Dollars

- In 2013, about 40 million family caregivers in the United States provided an estimated 37 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion in 2013, up from an estimated \$450 billion in 2009 (Reinhard, et al., 2015).
- The 2017 National Survey of Children's Health found that 13.3 million children under age 18 have special health care needs (Child and Adolescent Health Measurement Initiative, 2019). Including caregiving for children with special needs would add 4 to 8 million caregivers to the total number of caregivers and another \$50 to \$100 billion to the economic value of family caregiving (Feinberg, et al., 2011).
- Respite may help avoid or delay out-of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. These findings were recently corroborated by an updated review of the literature conducted by an Expert Panel on Respite Research, convened by ARCH with support from the Administration for Community Living (ARCH, 2018).

Stressed Working Caregivers Result in Massive Economic Costs to U.S. Businesses

- With at least two-thirds (66%) of family caregivers in the workforce (Matos, 2015), U.S. businesses 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).
- Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (Witters, 2011). Respite, by reducing caregiver burden for working family caregivers, could improve job performance, saving employers billions.
- 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 Children and Adults with Disabilities Improves Family Stability, Reduces Chances of Abuse and Out-of-Home Placements and Saves Money

- 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).

- A study of parents of children with autism found that respite was associated with reduced stress and improved marital quality (Harper, et al., 2013).
- In the first year of the study of impact of crisis nurseries for children and families in Illinois, caregivers using the crisis nursery reported decreased stress (79%) and improved parenting skills (73%). By year 3, 90% of caregivers reported decreased stress after crisis nursery use and 96% reported improved parenting skills. Caregiver perception of risk of maltreatment also improved from 73% of year one caregivers reporting reduced risk of maltreatment after crisis nursery use to 96% reporting the reduced risk in year 3 (Cole, et al., 2005).
- Respite may reduce administrative burdens and reduce facility-based placements, and can improve maternal employment (Caldwell, 2007).
- In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75% (NAC, 2012).
- in a study of primary caregivers of children with chronic illnesses, a statistically significant reduction in somatic complaints by caregivers and a decrease in the number of hospitalization days required by children were reported as a result of respite care (Sherman, B.R., 1995).
- 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).
- A study of Vermont's 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, E., 1999).

Respite Beneficial for Caregivers of Older Adults who Use Respite

- The National Family Caregiver Support Program (NFCSP) Outcome Evaluation found that NFCSP caregivers who received 4 or more hours of respite per week had a decrease in self-reported burden over time, while the comparison caregivers experienced an increase in self-reported burden. In addition, among caregivers who used NFCSP respite care, as the respite hours per week increased, so did the probability of a more favorable response regarding caregivers' perception that services helped them continue caregiving (Avison, et al., 2018).
- Users of a short-term residential caregiver education and respite program who had entered permanent residential care within 12 months was much lower than the comparison group (17.6% compared to 52.9%) that did not participate in the program (Gresham, et al., 2018).
- A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (Spillman and Long, 2007).
- 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).

- In a review of multiple studies investigating dementia care costs and outcomes, researchers found some evidence of the cost effectiveness of respite care when provided in out-of-home day respite programs (Knapp, M., 2013). Another meta study of caregiver support interventions for informal caregivers or community-dwelling frail elderly found evidence that respite care can be helpful in reducing caregiver depression, burden, and anger (Lopez-Hartmann, M, et al. 2012).
- 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, et al., 1992).
- In a meta-analysis of 75 research studies on caregiver interventions, respite was found to have small positive effects on caregiver health and level of burden and can have a positive effect on caregiver motivation in their caring roles, reducing fatigue, and improving psychological adjustment (Broady, T. and Aggar, C., 2017).
- In a systematic review of studies on the impact of respite care for caregivers of persons with dementia, six of the eight day care program studies indicated improvement in caregiver burden and stress related outcomes. Six of the seven day care program studies indicated decreased behavioral problems and possibly improved sleep quality for care recipients. When adult day care services are integrated with support and information services, a significant impact on care recipient behavioral problems and an increased delay in nursing home placement for the individuals who received the integrated programming were found (Vandepitte, et al., 2016).
- 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) Ongoing studies of this population using adult day services have consistently found significantly reduced caregiver stress levels that may be linked to improved caregiver health (Zarit, S.H., et al., 2014).

Respite Provided Across the Lifespan Yields Positive Outcomes

- The University of Nebraska Medical Center conducted a family caregiver survey of caregivers accessing respite through the Nebraska Lifespan Respite Network. When receiving respite care services, family caregivers reported decreases in stress levels, anxiety and depression, sleep problems, headaches and relationship strain. Even though 36% of family caregivers reported not having enough money at the end of the month to make ends meet, families overall reported being in a better financial situation when receiving respite. In 2017, 31% were considering an out-of-home placement prior to receiving respite compared to 23% currently considering an out-of-home placement. (Johnson, J., 2018)
- Alabama's Lifespan Respite's voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite (Alabama Department of Senior Services, 2018).
- 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. (Moss, J., 2004)

- Data from an outcome-based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages (Wade, C., et al., 2002)

What Does Respite Cost?

- For most 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 \$21/\$22. Also, the national median daily rate for adult day care is \$72. If these services are used periodically as respite, for example at a therapeutic rate of 4 hours of respite per week, the cost would still be far less than full time assisted living or nursing home care. The national median rate for assisted living is \$4,000 per month, while the national median daily rate for nursing home care in a semi-private room is \$245/day or \$7,441 per month (Genworth Financial, 2018 Cost of Care Survey).
- 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, 2002).

References

Abelson, A.G. (1999). Economic consequences and lack of respite care. *Psychological Reports*, 85, 880-882.

Alabama Department of Senior Services (2018). *Alabama's Lifespan Respite Sustainability Program Semi-Annual Performance Report, March 30, 2018*. Huntsville, AL: Author.

Avison, C, Brock, D, Campione, J, Hasell, S, Rabinovich, B, Ritter, R, Severynse, J, Yang, D-H (2018) *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.

ARCH and Child Welfare League of America (2002), *Planned and Crisis Respite for Families with Children: Results of a Collaborative Study*.

https://archrespite.org/images/ARCH/Planned_and_Crisis_respite.pdf

ARCH National Respite Network and Resource Center (2018). *Annotated Bibliography of Respite and Crisis Care Studies*. Chapel Hill, NC: Author.

https://archrespite.org/images/docs/Bibliographies/Annotated-Bibliography_Web_2018.pdf

Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *J of the Australasian Rehabilitation Nurses' Association*, 20 (2), 5-11

Bruns, E.J.& Bujrchar, J.D. (2000) Impact of Respite Care Services for Families with Children Experiencing Emotional and Behavioral Problems. *Children's Services: Social Policy, Research, and Practice*, 3(1), 39-61.

Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability and Society*, 549-562.

Chang, J.I., Karuza, J., Katz, P.R., & Klingensmith, K. (1992). Patient outcomes in hospital-based respite: A study of potential risks and benefits. *Journal of the American Board of Family Practice*, 5, 475-481

Child and Adolescent Health Measurement Initiative. 2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [04/07/19] from www.childhealthdata.org. CAHMI: www.cahmi.org.

Cole, S.A., Wehrmann, K.C., Dewar, G. and Swinford, L. (2005). Crisis nurseries: Important services in a system of care for families and children. *Children and Youth Services Review*, 27 (9): 995-1010.

Feinberg, Lynn, Reinhard, S.C., Houser, A. and Choula, R. (2011) *Valuing the Invaluable: 2011 Update. The Growing Contributions and Costs of Family Caregiving*. Washington, D.C.: AARP Public Policy Institute, 2011.

Genworth Financial, 2018 Cost of Care Survey. <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.

Harper, A; Dyches, TT; Harper, J; Roper, SO; and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, March 2013.

Johnson, J., Swanson, S., and Falk, K. (2018). *Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families, 2015-2017*. Munroe-Meyer Institute and the Interdisciplinary Center of Program Evaluation, University of Nebraska Medical Center.

Knapp, M., Lemmi, V., and Romeo, R. (2013). Dementia care costs and outcomes: a systematic review. *Int J Geriatr Psychiatry*, 28: 551-561.

Kosloski K. & Montgomery, R. J.V. (1995). The Impact of Respite Use on Nursing Home Placement. *Gerontologist*, 35, (1), 67-74.

Leon, J., Cheng, C. K., & Neumann, P. J. (1998). Alzheimer's disease care: costs and potential savings. *Health Affairs*, 17(6), 206 -216.

Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12: 1-14.

Mandell, D.S., Ming Xie, M.S., Morales, K.H., Lawer, L., McCarthy, M., and Marcus, S.C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Arch Pediatr Adolesc Med*, 166 (1): 68-73.

Matos, K. (2015). Highlights from the 2014 Older Adult Caregiver Study. New York, NY: Families and Work Institute. <http://www.familiesandwork.org/downloads/2014-Older-Adult-Caregiver-Study.pdf>

Mausner, S. (1995). Families helping families: An innovative approach to the provision of respite care for families of children with complex medical needs. *Social Work in Pediatrics*, 95-106.

MetLife Mature Market Institute. (2006). *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*. <http://www.caregiving.org/data/Caregiver%20Cost%20Study.pdf>

Moss, J. (2004). *Strategies to improve access to Medicaid home- and community-based services: Hearing testimony before the Committee on Finance, United States Senate, One Hundred Eighth Congress, second session, April 7, 2004*

National Alliance for Caregiving. (2012). *Multiple Sclerosis Caregivers*. Washington, DC: Author. http://www.caregiving.org/pdf/research/MSCaregivers2012_FINAL.pdf

Reinhard, S. C.; Friss Feinberg, L.; Choula, R.; Houser, A. (2015) *Valuing the Invaluable: 2015 Update. Undeniable Progress, but Big Gaps Remain*. Washington, D.C: AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

Sherman, B.R. (1995). Impact of home-based respite care on families of children with chronic illnesses. *Children's Health Care*, 24(1), 33-45.

Spillman, Brenda C, and Long, S, prepared for the USDHHS (U.S. Department of Health and Human Services). (2007). *Does high caregiver stress lead to nursing home entry?* Washington, DC: Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy. January 26, 2007 DHHS Report. <https://aspe.hhs.gov/basic-report/does-high-caregiver-stress-lead-nursing-home-entry>

Theis, SL, Moss, JH, and Pearson, MA (1994). Respite for caregivers: An evaluation study. *Journal of Community Health Nursing*. 11(1): 31-44.

Vandepitte, S.V., Noortgate, N.V.D., Putman, K., Verhaeghe, S., Verdonck, C. and Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *Int J Geriatr Psychiatry*, 31: 1277-1288.

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. https://archrespite.org/images/docs/Phase_II_Outcome_Results.pdf

Witters, Dan. The Cost of Caregiving to the U.S. Economy. *Gallup Business Journal*, December 2011. <http://businessjournal.gallup.com/content/151049/Cost-Caregiving-Economy.aspx>

Zarit, S.H., Stephens, M.A., Townsend, A., & Greene, R. (1998). Stress Reduction for Family Caregivers: Effects of Adult Day Care Use. *Journal of Gerontology: Social Sciences*, Vol. 53B, No. 5, S267-S277B.

Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almeida, D.M., Rovine, M.J., Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatry*.22(12):1592-602.

Prepared by the National Respite Coalition, Updated April 2019. For more information, please contact Jill Kagan at jkagan@archrespite.org or at 703-256-2084.