# **Guidebook Appendix**

## Study Reports, Handbooks, Planning Guides, and Workbooks

### 2012

#### Cost of Care Report. Genworth Financial. 2012

Research shows that about 70 percent of people age 65 or older will need long term care services at some point in their lifetime. And while most people think of long term care as impacting only those in senior years, 40 percent of people currently receiving long term care services are ages 18 to 64. The Genworth 2012 Cost of Care Survey can help families evaluate options to address the increasing cost of long term care. For the ninth consecutive year, Genworth has surveyed the cost of long term care across the U.S. to help Americans appropriately plan for the potential cost of this type of care in their preferred location and setting. The most comprehensive study of its kind, Genworth's 2012 Cost of Care Survey covers nearly 15,300 long term care providers in 437 regions nationwide. This report provides average costs (by state) for home care providers, adult day health care facilities, assisted living facilities, and nursing homes.

Available online (will need to download report as a pdf file):

http://www.genworth.com/content/non\_navigable/corporate/about\_genworth/industry\_expertise/cos t\_of\_care.html

*National Study of Employers.* Families and Work Institute and the Society for Human Resource Management (SHRM); authored by Kenneth Matos and Ellen Galinsky. 2012.

Families and Work Institute's 2012 National Study of Employers (NSE) is the most comprehensive and far-reaching study of the practices, policies, programs and benefits provided by U.S. employers to address the changing needs of today's workforce and workplace. The NSE is based on the Institute's landmark 1998 Business Work-Life Study (BWLS) and has been conducted three additional times since the BWLS survey was completed (2005, 2008 and 2012). The 2012 NSE sample includes 1,126 employers with 50 or more employees—75% are for-profit employers and 25% are nonprofit organizations; 18% operate at only one location, while 82% percent have operations at more than one location. Families and Work Institute (FWI) designed the questionnaire, and Harris Interactive, Inc. conducted the interviews on behalf of FWI. The results of the survey are being released with the Society for Human Resource Management (SHRM) as an integral part of the FWI-SHRM When Work Works initiative. Findings reveal that both employers and employees can benefit from effective and flexible workplaces. Employees benefit from having higher quality jobs and more supportive workplaces that are less likely to negatively affect their personal and family lives, while employers benefit from having more engaged employees, higher retention and potentially lower health care costs.

#### Available online:

#### http://familiesandwork.org/site/research/reports/NSE\_2012.pdf

*Best Practices in Workplace Eldercare.* National Alliance for Caregiving and ReACT (Respect a Caregiver's Time). March 2012.

The introduction to the study includes a good summary of the history of eldercare programs offered by employers. This study is designed to look at what employers are doing today for their employees with eldercare responsibilities and to highlight innovations. Those who participated in the study shared information about their eldercare programs via phone using a semi structured interview that explored the history of the program, the program elements, how it is marketed, the utilization rates, how the program is evaluated and the benefits

to the employer. Each respondent was also asked about other companies who might be

included in the study. The 17 companies participating in the study represented an array of

industries including: Professional/Non-profit Associations; the Financial Industry; Health Care Providers; Higher Education; Insurance; Manufacturing; Media; the Pharmaceutical industry, and IT-related industries. Brief case studies of all of the employers are found in the appendix of the report. Note: And finally, despite the SHRM survey (see report listed above) that showed that employers were reducing benefits and programming for caregiving employees, about one-third of the respondent employers in this study report that they had begun their eldercare program in the past 5 years with most of those starting the program less than 3 years ago.

Available online:

http://www.caregiving.org/pdf/research/BestPracticesEldercareFINAL.pdf

### 2011

*Valuing the Invaluable: 2011 Update – The Growing Contributions and Costs of Family Caregiving.* Feinberg, Reinhard, Houser& Choula, AARP Public Policy Institute. 2011.

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. There is a good section on the impact of caregiving on work. Highlighted in this section is the following information: The great majority (74 percent) of family caregivers have worked at a paying job at some point during their caregiving experience, and more than half (58 percent) are currently employed either full-time or part-time, balancing work with their caregiving role.35 When it becomes stressful to juggle caregiving activities

with work and other family responsibilities, or if work requirements come into conflict with caregiving tasks, some employed caregivers make changes in their work life. Nearly seven in ten (69 percent) caregivers report making work accommodations because of caregiving. These adjustments include arriving late/leaving early or taking time off, cutting back on work hours, changing jobs, or stopping work entirely. Family caregivers with the most intense level of caregiving (those who provide 21+ hours of care each week), those with a high burden of care, or those who live with their care recipient are especially likely to report having to make workplace accommodations

Available online:

http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf

*The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents.* Westport, CT: MetLife Mature Market Institute. 2011.

Nearly 10 million adult children over the age of 50 care for their aging parents. These family caregivers are themselves aging as well as providing care at a time when they also need to be planning and saving for their own retirement. *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents* was produced by the MetLife Mature Market Institute in partnership with the National Alliance for Caregiving and

the Center for Long Term Care Research and Policy at New York Medical College. The study analyzes data from the 2008 panel of the National Health and Retirement Study (HRS) combined with estimates to determine the extent to which older adult children provide care to their parents, the roles gender and work play in that caregiving, and the potential cost to the caregiver in lost wages and future retirement income as a result of their support. Among the findings are the following:

- The percentage of adult children providing personal care and/or financial assistance to a
  parent has more than tripled over the past 15 years. Currently, a quarter of adult children,
  mainly Baby Boomers, provide these types of care to a parent.
- The total estimated aggregate lost wages, pension, and Social Security benefits of these caregivers of parents is nearly \$3 trillion.
- For women, the total individual amount of lost wages due to leaving the labor force early because of caregiving responsibilities equals \$142,693. The estimated impact of caregiving on lost Social Security benefits is \$131,351. A very conservative estimated impact on pensions is approximately \$50,000.
- Thus, in total, the cost impact of caregiving on the individual female caregiver in terms of lost wages and Social Security benefits equals \$324,044.
- For men, the total individual amount of lost wages due to leaving the labor force early because of caregiving responsibilities equals \$89,107. The estimated impact of caregiving on lost Social Security benefits is \$144,609. Adding in a conservative estimate of the impact on pensions at \$50,000, the total impact equals \$283,716 for men, or \$303,880 for the average male or female caregiver 50+ who cares for a parent.

- Working and non-working adult children are almost equally as likely to provide care to parents in need.
- Overall, caregiving sons and daughters provide comparable care in many respects, but daughters are more likely to provide basic care and sons are more likely to provide financial assistance.
- Adult children 50+ who work and provide care to a parent are more likely to have fair or poor health than those who do not provide care to their parents.

Assessing the long-term financial impact of caregiving for aging parents on caregivers themselves, especially those who must curtail their working careers to do so, is especially important, since it can jeopardize their future financial security. There is also evidence that caregivers experience considerable health issues as a result of their focus on caring for others. The need for flexibility in the workplace and in policies that would benefit working caregivers are likely to increase in importance as more working caregivers approach their own retirement while still caring for an aging parent.

Available online:

http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf

## 2010

Beyond Dollars: The True Impact of Long Term Caring. Genworth Financial. 2010.

Reports the results of the survey of more than 800 consumers with personal involvement in a long term care event lasting more than 30 days. Page 12 contains data on career impacts of caregiving.

Available online:

http://www.genworth.com/content/non\_navigable/corporate/about\_genworth/industry\_expertise/cos t\_of\_care.html

*Prepare to Care – A Planning Guide for Families,* AARP Foundation, 2010.

A practical guide for caregivers, outlining five steps: Step 1: Prepare to Talk Step 2: Form Your Team Step 3: Gather and Organize Information Step 4: Make a Plan Step 5: Take Action

Available online (will need to download booklet as a pdf file):

http://www.aarp.org/aarp-foundation/info-2010/prepare-to-care.html

Also see: <a href="http://www.sylexcom.net/test/docs/care.html">http://www.sylexcom.net/test/docs/care.html</a>

#### Caregiving: Workplace Support Checklist. Heath Advocate. 2010.

This publication accompanies Health Advocate's webinar, "Caregiving: The Impact on the Workplace" cosponsored by the National Women's Health Resource Center, the leading independent health information source for women. This booklet outlines the findings of research about the scope, impact and costs of caregiving and its role in caregiving-related

absences, turnover, replacement, lost productivity and stress-related illness. The research also reviews successful strategies demonstrated to help employees better manage the dual responsibilities of caregiving and work.

Available online:

http://www.healthadvocate.com/downloads/webinars/caregiving-checklist.pdf

*Caregivers in the Workplace: Best Practices for Workers with Elder Caregiving Responsibilities.* United Way of Waukesha, Wisconsin, and The Caregiver Connection. 2010.

This report provides a good historical perspective of the needs of employed caregivers, various ways businesses have supported employed caregivers of elders, and what would help to enhance this effort. This report also includes the current practices that have been shared by the businesses involved in the United Way's Caregiver Support Consortium of Waukesha County (Wisconsin) through involvement in its efforts or participation in Caregiver Simulation.

Available online:

http://whocaresforyou.org/Libraries/Downloads/Caregivers\_in\_the\_Workplace.sflb.ashx

*The Elder Care Study: Everyday Realities and Wishes for Change.* New York, NY: Families and Work Institute. Authored by Kerstin Aumann, Ellen Galinsky, Kelly Sakai, Melissa Brown, & James T. Bond. 2010.

Based on a nationally representative sample of employed caregivers, drawn from the Families and Work Institute's ongoing National Study of the Changing Workforce (NSCW). From the 2008 NSCW, caregivers—both those who were currently providing care or who had provided care to someone who had died within the past five years—were invited to participate in an telephone interview. Highlights from findings include:

- Almost one in two individuals in the workforce (42% or nearly 54.6 million employees) have provided elder care over the past five years.
- Among those who have provided care in the past five years, almost half (44%) have cared for more than one person.
- 17% of workers in the workforce are currently providing elder care.
- Among the entire workforce, women (20%) and men (22%) are equally likely to have provided family care in the past five years and equally likely to provide care at the current
- ime (9% versus 8%).
- Although women and men provide care in roughly equal numbers, there are many differences in the way that these experiences play out in their lives. Women are more likely (44%) than men (38%) to provide family care on a regular basis rather than on an intermittent basis. In addition, women spend more time than men providing care on average. Women spend 9.1 hours a week providing care (an average of 6.4 hours providing in-person care and an average 2.7 hours providing indirect care), while men spend 5.7 hours as caregivers (an average 3.4 hours providing in-person care and an average 2.2 hours providing indirect care).
- Many of these caregivers are in the sandwich generation—46% of women who are caregivers and 40% of men also have children under the age of 18 at home.
- Just under half of the workforce (49%) expect to be providing elder care for a familymember in the coming five years.
- Family caregivers work as many hours on average (45 hours) as those without caregiving responsibilities (44 hours).
- Although most working caregivers (55%) report that they would prefer to work fewer hours, only 23% have actually reduced their hours.
- Not surprisingly, many are experiencing a time famine: 71% report not having enough time for their children, 63% report not having enough time for their spouse/partner and 63% report not having enough time for themselves. Interestingly, men who are providing care are now more likely than women caregivers to experience work-life conflict.
- 49% of men experience "some" or "a lot" of conflict compared with 42% of women. Available online:

### http://familiesandwork.org/site/research/reports/elder\_care.pdf

*The Metlife Study of Working Caregivers and Employer Health Care Costs*. Marture Market Institute (MMI), Metropolitan Life Insurance Company, and the National Alliance for Caregiving (NAC). 2010, February.

This is a report of a collaborative project of the MMI, NAC, and the University of Pittsburgh, and focuses on how caregiving, employer health costs, and employer-sponsored wellness benefits intersect. It reports on a case-study analysis of anonymous aggregate responses from 17,097 U.S. employees of a major multi-national manufacturing corporation who completed health risk assessment (HRA) questionnaires. Nearly 12% of these employees reported caregiving for an older person, and generally those caregiving employees reported poorer health and more chronic disease than non-caregivers. The findings indicate that there is an 8% differential in increased health care costs between caregiving and non-caregiving employees, potentially costing U.S. employers an extra estimated \$13.4 billion per year. Since the employees in the study are caring for the elderly, the estimates provided are conservative given that those caring for a spouse or a younger family member were not included. Although the case study approach limits the extent to which the results can be generalized, the analysis provides the first structured approach to understanding what these eldercare-related employee health costs might be.

Available online:

http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf

### 2009

Caregiving in the U.S. National Alliance for Caregiving and AARP. 2009.

This study was funded by MetLife Foundation and conducted for the National Alliance for Caregiving in collaboration with AARP. Involved interviews with 1,480 caregivers chosen at random. The study was designed to replicate similar studies conducted in 2004 and 1997 and includes, for the first time, a sampling of those caring for children as well as those caring for adults over the age of 18. Among the findings: American caregivers are predominantly female (66%) and are an average of 48 years old. Most care for a relative (86%), most often a parent (36%). Seven in ten caregivers care for someone over age 50. One in seven caregivers provides care, over and above regular parenting, to a child with special needs (14%). Caregiving lasts an average of 4.6 years. The study also revealed that both caregivers of adults and their care recipients are now older than their counterparts were five years ago. Among caregivers of adults (ages 18 or older), the average age of the caregiver rose from 46 to 49. The change can be attributed to a decline among younger caregivers (those under the age of 50) and a shift upward among caregivers age 50 to 64. Among caregivers of adults, the average care recipient's age increased from 67 to 69, mainly because of an increase in the percentage age 75 or older (from 43% to 51%).

Available online:

http://www.caregiving.org/data/Caregiving\_in\_the\_US\_2009\_full\_report.pdf

*Caregiving in the U.S: A Focused Look at Those Caring for Someone Age 50 or Older.* National Alliance for Caregiving and AARP. November 2009.

This report is based on the same national survey referenced above, but focuses on those caring for adults age 50 or older. Among the findings was the following: Approximately three-fourths of caregivers have worked while caregiving. While this has remained consistent since our last study, there has been an increase in the proportion who say they have had to make a workplace accommodation due to

caregiving. For example, there has been an increase in the most common workplace accommodation having to go into work late, leave early, or take time off during the day to fulfill their caregiving responsibilities. Caregivers who have worked while being a caregiver are also more likely to say they need help balancing their work and family responsibilities which represents another potential area for caregiver interventions.

Available online:

http://assets.aarp.org/rgcenter/il/caregiving\_09.pdf