



## 2011 Respite and Caregiving Fact Sheet

### Making the Case for Respite among US Caregivers Across the Lifespan

- During the past year, an estimated 65.7 million people in the US served as unpaid family caregivers to an adult or child (*National Alliance for Caregiving and the AARP, Caregiving in the US, November 2009*)
- Caregiving is a lifespan issue. While caring for the aging population is a growing issue, currently more than half of care recipients (56%) are under age 75, and almost one-third (28%) are under age 50 (*NAC and AARP, 2009*).
- Many family caregivers are in the sandwich generation—46% of women who are caregivers of an aging family member and 40% of men also have children under the age of 18 at home (*Aumann, Kerstin and Ellen Galinsky, et al. 2008. The Eldercare Study: Everyday Realities and Wishes for Change, Families and Work Institute*).
- Nationwide, there are approximately 1.3 to 1.4 million young caregivers who are between the ages of 8 and 18 (*National Alliance for Caregiving, Young Caregivers in the U.S., 2005*).
- More than six and a half million children across the country are living in households maintained by grandparents or other relatives. More than 2.5 million grandparents have the primary responsibility for meeting the basic needs of their grandchildren. About 1.7 million grandparents are age 59 and younger, whereas 828,000 are age 60 and older. Nineteen percent of these caregivers are living at or below poverty and almost 60 percent are still in the labor force (*U.S. Census Bureau's 2006-2008 American Community Survey (ACS)*).
- Kinship caregivers are four times more likely than foster caregivers not to have graduated from high school and three times more likely to have an annual household income of less than \$20,000. Yet, kinship caregivers are less than half as likely as foster caregivers to receive any type of financial support, about four times less likely to receive any form of parent training and seven times less likely to have peer support groups or respite care (*Christina Sakai, MD; Hua Lin, PhD; Glenn Flores, MD (2011). Health Outcomes and Family Services in Kinship Care: Analysis of a National Sample of Children in the Child Welfare System. Archives of Pediatric Adolescent Medicine. 65(2):159-165*).
- Nearly 90% of family caregivers caring for someone over the age of 18 do not use respite services. Among family caregivers of children under 18, 81% do not use respite (*NAC and AARP, 2009*).

- In a study of a nationally representative profile of noninstitutionalized children ages 0-17 who were receiving support from the Supplemental Security Income (SSI) program because of a disability, only 8% reported using respite care but three quarters of families had unmet respite needs (*Rupp, K, Davies, PS, Newcomb, C, Iams H, Becker C, Mulpuru, S, Ressler, S, Romig, K, and Miller, B. (2005-2006). A profile of children with disabilities receiving SSI: Highlights from the National Survey of SSI Children and Families. Soc. Secur. Bull. 66 (2): 21-48*)
- While the NAC/AARP survey did not ask why family caregivers did not use respite, such barriers have been well documented. They include cost, restrictive eligibility criteria, waiting lists, accessibility, limited or no respite options, inadequate supply of trained providers or appropriate programs, lack of information, or feelings related to lack of trust of outside providers, guilt, or non-identification as a family caregiver (*National Respite Coalition Written [Testimony](#) to the House Subcommittee on Labor, Health and Human Services, and Education Appropriations. April 12, 2010*).
- Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (*NAC and AARP, 2009*).

### **Family Caregivers at Higher Risk for Emotional and Physical Consequences**

- A majority of family caregivers (51%) caring for someone over the age of 18 have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31% of all family caregivers were identified as “highly stressed” (*NAC and AARP, 2009*).
- Half of all family caregivers (53%) say that their caregiving takes time away from family and friends. Of those who sacrificed this time, 47% feel high emotional stress (*NAC and AARP, 2009*).
- While family caregivers of children with special health care needs are younger than caregivers of adults, they give lower ratings to their health. Only four out of ten consider their health to be *excellent* or *very good* (44%) compared to six in ten (59%) caregivers of adults; 26% say their health is fair or poor, compared to 16% of those caring for adults. Caregivers of children are twice as likely as the general adult population to say they are in fair/poor health (26% vs 13%) (*Provisional summary Health Statistics for US Adults, National Health Interview Survey, 2008, dated August 2009*).
- In a 2009 survey of family caregivers, despite the fact that among the most frequently reported unmet needs of family caregivers were “finding time for myself” (32%), “managing emotional and physical stress” (34%), and “balancing work and family responsibilities” (27%), only 11% of caregivers of adults 18+ use respite (*NAC and AARP, 2009*).

### **Family Caregiver Well-Being is Important to Care Recipient Health**

(as reported in [APA's Family Caregiver Briefcase](#))

- The decline of family caregiver health is one of the major risk factors for institutionalization of a care recipient, and there is evidence that care recipients whose caregivers lack effective coping styles or have problems with depression are at risk for falling, developing preventable secondary complications such as pressure sores and experiencing declines in functional abilities (*Elliott & Pezent, 2008*).

- Care recipients may also be at risk for encountering abuse from caregivers when the recipients have pronounced need for assistance and when caregivers have pronounced levels of depression, ill health, and distress (*Beach et al., 2005; Williamson et al., 2001*).

### **Family Caregivers of Veterans**

- Among those surveyed, only 15% of family caregivers caring for veterans *whose illness, injury or condition is in some way related to military service* has received respite services from the VA or some other community organization within the past 12 months. Caregivers whose veterans have PTSD are only about half as likely as other caregivers to have received respite services (11% vs. 20%) (*National Alliance for Caregiving, Caregivers Of Veterans - Serving On The Homefront, November 2010*).
- Sixty-eight percent of veterans' caregivers reported their situation as highly stressful compared to 31 percent of caregivers nationally who feel the same and three times as many say there is a high degree of physical strain (40% vs. 14%) (*NAC, 2010*).
- Veterans' caregivers specifically asked for up-to-date respite resource lists of respite providers in their local communities and help them find services – the very thing Lifespan Respite is charged to provide (*NAC, 2010*).

**For the Economic Costs of Caregiving and the Benefits of Respite see:**

**[Benefits and Cost-Savings Due to Respite](#): Family Caregivers Save the Government Billions of Dollars—Respite Saves the Caregivers, *National Respite Coalition, updated 2010*; and**

**[Making the Case: Saving Your State's Caregiver Support Programs](#) --Talking Points for Advocates, Administrators, Providers and Caregivers, *Family Caregiver Alliance, December 2009*.**