



The Need for and Benefits of Respite for Children and Young Adults

Children with Special Health Care Needs and their Family Caregivers

- ❑ According to the most recent report from the US Health Resources and Services Administration, 14 to 19 percent of U.S. children have a chronic physical, developmental, behavioral or emotional condition. (*Health Resources and Services Administration (HRSA), 2011*).
- ❑ An estimated 4.5 to 6.3 million children and youth in US suffer from a serious mental health condition (about 10%); about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need (*Substance Abuse and Mental Health Administration (SAMHSA), 2011*).
- ❑ More than 6.5 million children across the country are living in households maintained by grandparents or other relatives. As for the caregivers, more than 2.5 million grandparents have the primary responsibility for meeting the basic needs of their grandchildren; nearly 20% of these families are living at or below the federal poverty level (*American Community Survey (ACS) 2006-2008. Summary Table S1002, Grandparents*).
- ❑ An estimated 16.8 million unpaid caregivers provide care to a child with special needs under the age of 18 in the U.S. The caregiving is defined as being due to a medical, behavioral, or other condition or disability—whether the condition is ongoing or a serious short-term medical condition, an emotional or behavior problem, or a developmental problem. Caregivers of children are less likely than caregivers of adults to be caring for just one person (51% vs. 68% respectively). Half of caregivers of children are providing care to their own son or daughter (55%). Child care recipients are also commonly a grandchild (18%), another relative such as a niece or nephew (13%), a friend (8%), or some other non-relative (5%) (*National Alliance for Caregiving (NAC) and AARP, 2009*).

Respite Use/Access Limited

- ❑ Eighty-one percent of family caregivers of children with special health care needs do not use respite. In spite of their interest in finding time and life balance for themselves, 86% of caregivers caring for young adults ages 18-49 have not used a respite or companion service to free up their time (*NAC and AARP, 2009*).
- ❑ 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, limited or no respite options, accessibility, 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 (NRC), 2010*).

- ❑ 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, et al, 2005-06*)
- ❑ Kinship caregivers are 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 (*Sakai, C, et al, 2011*).

Family Caregivers of CSHCN Experience Stress, Poor Health, and Social Limitations

- ❑ Six out of ten caregivers of children (60%) say caregiving limits the amount of time they spend with other family and friends. When asked on what topics they needed more information or help, “managing their own emotional/physical stress” (46%) and “finding time for themselves” (46%) were among their top two responses (*NAC and AARP, 2009*).
- ❑ Among children who live with their mothers, 52.2% of children with special health care needs (CSHCN) compared to 42% of non-CSHCN have mothers who are not in excellent or very good physical and mental health, regardless of the mother's marital status. This discrepancy between children with and without special health care needs was evident in fathers' health status as well (*HRSA, 2011*).
- ❑ CSHCN are more than twice as likely to have a parent who reported “usually or always” feeling stressed (*HRSA, 2011*).
- ❑ A majority (64%) of family caregivers of children with special needs ages 0-17 experience physical strain; 17% experience high levels of physical strain (*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 (*NAC and AARP, 2000*).
- ❑ 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*).

Economic Consequences of Family Caregiving of CSHCN

- ❑ Three out of four family caregivers of children with special needs report making changes to their work situation. Those caring for a child are three times as likely as those caring for an adult to have had some of the more severe impacts on their employment situation: cutting hours or taking a less demanding job, giving up work entirely, and losing benefits. They are also more likely to have taken a leave of absence (*NAC and AARP, 2009*).

- ❑ Caregivers of children are more likely to feel at least some financial hardship as a result of caring for their loved one than their counterparts who care for an adult, and twice as likely to feel strong financial hardship. One in three of caregivers of children have sought financial assistance on behalf of the child (32%) (*NAC and AARP, 2009*).
- ❑ 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*)
- ❑ 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 (*Sakai, C, et al, 2011*).

Health and Economic Benefits of Respite for CSHCN and Their Families

- ❑ 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 primary caregivers of children with chronic illnesses showed a statistically significant reduction in somatic complaints, and a decrease in the number of hospitalization days required by children, as a direct result of respite care (*Sherman, B.R., 1995*).
- ❑ Research at Oklahoma State University found the number of hospitalizations, as well as the number of medical care claims, decreased as the number of respite care days increased (*FY 1998 OK Maternal and Child Health Block Grant Annual Report, 1999*).
- ❑ A Massachusetts social services program providing family-centered respite 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*).
- ❑ 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 CWLA, 2002*).

Respite Needs Move on into Adulthood of CSHCN

- ❑ According to a study conducted by the National Alliance for Caregiving and AARP in 2009, 11.1 million family caregivers provide care to an adult ages 18-49. Of these, 39% care for their own

child and 14% care for a sibling. The physical strain, emotional stress and financial hardship felt by caregivers of younger adults is similar to that felt by caregivers of children with special needs (NAC and AARP, 2009).

- ❑ In the NAC/AARP study, three out of the four top areas in which family caregivers of adults ages 18-49 would like help or information relate to helping themselves cope with or adjust to their caregiver role: managing their emotional stress (38%), finding time for themselves (32%), and balancing work and family (30%). Keeping their recipient safe at home rounds out the top four areas (35%) (NAC and AARP, 2009).
- ❑ Nearly 5 million people with intellectual and developmental disabilities (I/DD) live in the US. The vast majority (60%) live at home with family caregivers. If the caregivers are parents, they do not qualify for the National Family Caregiver Support Program (NFCSP). Twenty-five percent live with family caregivers who are over the age of 60. (*The Arc, personal communication, 2011*).
- ❑ A recent survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) conducted by The Arc found:
 - 58% of parents/caregivers report spending more than 40 hours per week providing support for their loved one with I/DD, including 40% spending more than 80 hours a week.
 - Nearly half (46%) of parents/caregivers report that they have more caregiving responsibilities than they can handle.
 - Vast majority of caregivers report that they are suffering from physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time.
 - 1 out of 5 families (20%) report that someone in the family had to quit their job to stay home and support the needs of their family member.
 - More than 75% of family caregivers caring for adult children with developmental disabilities could not find respite services (*The Arc, 2011*).

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