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**LANDMARK STUDY SHOWS 1.4 MILLION CHILDREN ARE  
CAREGIVERS, INCLUDING 400,000 UNDER THE AGE OF 11**

*Young Caregivers Most Likely to Live in Lower-Income and Single-Parent Homes;  
More Likely to Suffer From Depression and Anxiety*

**SEPTEMBER 14, 2005** -- As many as 1.4 million children in the United States between the ages of 8 and 18 provide care for an older adult, including approximately 400,000 youngsters who are between the ages of 8 and 11. These and other data are contained in a landmark study – the first of its kind in the United States – titled *Young Caregivers in the U.S.*, issued today by the **National Alliance on Caregiving** and the **United Hospital Fund** and funded by the US Administration on Aging.

Researchers also found that young caregivers – half of whom are boys – are more likely to come from households with lower incomes; are less likely to be from a two-parent home; and are more likely than their non-caregiving counterparts to experience depression and anxiety.

“Across the nation today, almost 1.4 million children and teens have some responsibility for the care of an older adult—most often a parent or grandparent,” said Gail Gibson Hunt, Executive Director of the National Alliance for Caregiving. “The good news is that most are not providing care all alone. The bad news is that many among this vulnerable group experience behavior problems, depression, and disruptions in school.”

In the U.S., little is known about these understudied and underserved children, who outnumber the combined total of students in grades 3-12 in New York City, Chicago, and the District of Columbia. All previous major U.S. caregiver surveys have included only those over the age of 18. The experience of young caregivers has, however, been studied in the United Kingdom, Australia, and New Zealand. There are some small studies of former child caregivers in the United States.

“We generally think of children as needing care, not providing it,” said Carol Levine, Director of the United Hospital Fund’s Families and Health Care Project. “Previous international studies show that caregiving can profoundly influence children’s lives and development in a multitude of ways. We are seeking ways to support these children and their families. It is essential to

involve young caregivers themselves in developing services appropriate to their ages and developmental levels.”

Hunt and Levine believe that new resources should be earmarked to fund new studies about caregiving and its impact on young providers. The researchers also called for social service, health care and caregiver organizations to collaborate with established groups that serve the needs of families and children including schools, youth organizations like Ys and scouting, religious groups and other service providers in order to develop appropriate family-centered services.

Josefina G. Carbonell, Assistant Secretary for Aging at the US Department of Health and Human Services said, “This report contains important information of a new subgroup of family caregivers in the United States. It will be useful to the Administration on Aging and our Network as they plan for the future of long-term care, the role of caregivers, and the National Family Caregiver Support Program.”

## **FINDINGS**

### **Child Caregiver Profiles:**

The study, which compared groups of child caregivers with their non-caregiving peers, found that:

- Child caregivers fall into three approximately equal age groups: 31% are aged 8 to 11; 38% are aged 12 to 15; and 31% are aged 16 to 18.
- Child caregivers are evenly balanced by gender, with boys making up 49% of the total, and girls 51%. There is an indication that boys seem to have greater difficulties than girls, particularly in feelings of isolation and sadness and in behavior and school problems.
- Child caregivers tend to live in households with lower incomes than non-caregivers, and they are less likely than non-caregivers to live in two-parent households.
- Seven in ten child caregivers (72%) are caring for a parent or grandparent. One in ten (11%) is helping a sibling.

### **Responsibilities and Tasks**

- About half (49%) of the caregivers report that they spend “a lot of time” caregiving.
- Over half (58%) of the child caregivers help their care recipient with at least one Activity of Daily Living (ADL) such as bathing, dressing, getting in and out of bed or chair, toileting, and feeding.
- Nearly all young caregivers help with shopping, household chores, and preparing meals. Nearly all also spend some time just “keeping the care recipient company.”
- A third (30%) of child caregivers help with medications and 17% help the care recipient communicate with doctors or nurses.
- Of caregivers aged 12 and over, 15% help make calls and arrangements for other people to help the care recipient.

- While at least three quarters of child caregivers have help with tasks, caregivers in minority households are much less likely than those in nonminority households to report that others help them with caregiving tasks, including chores, meal preparation, and dressing.
- 35% of child caregivers in minority households report having no help in dispensing medications, compared to 11% in non-minority households.

**Impact on behavior/school:**

- According to parents' reports of their child's behavior, child caregivers tend to exhibit more anxious or depressive behavior than noncaregivers. For example, caregivers are more likely than non-caregivers to feel at least some of the time that no one loves them. This is evident among younger children aged 8 to 11 (36% vs. 20%) and among 12- to 18-year-olds (23% vs. 14%).
- A larger share of caregivers aged 12 to 18 have behavior problems than do noncaregivers. In particular, they are more likely to have trouble getting along with teachers (27% vs. 14%), to bully or act mean toward others (24% vs. 9%), and to associate with kids who get into trouble (17% vs. 9%).
- On the positive side, 64% of child caregivers report feeling appreciated "a lot" for what they do compared to 53% of noncaregivers.
- Some child caregivers report that their responsibilities have affected their school work or school activities. For example, 20% say their caregiving has made them miss a school or after-school activity, 15% say it has kept them from doing school work, and 8% say it has made them miss homework deadlines.

The survey, *Young Caregivers in the U.S.*, was conducted by Mathew Greenwald & Associates, Inc., a research firm in Washington. For additional details on methodology, *see attachment A*.

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**ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING:** NAC is a non-profit coalition of 40 national organizations focused on issues of family caregiving. The Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

**ABOUT THE UNITED HOSPITAL FUND:** The Fund is a health services research and philanthropic organization whose mission is to shape positive change in health care for the people of New York and the nation.

## ATTACHMENT A

### METHODOLOGY

The survey, *Young Caregivers in the U.S.*, was conducted by Mathew Greenwald & Associates, Inc., a research firm in Washington. There were two parts: a random sample of 2,000 U.S. households was surveyed to find out whether any child aged 8 to 18 provides unpaid help or care to any person. The question specified that the care recipient “need not live with you, and the care may include help with personal needs, meals, household chores, shopping, paperwork, medication, getting around, or visiting regularly to see how they are doing.” In this way not all children who live in a household with a disabled or ill adult would be classified as a caregiver. This survey determined the prevalence rate in the U.S. of 3.2% of the 28.4 million households who have a child aged 8 to 18 living there.

The second component used a two-stage methodology. The first stage identified child caregivers to be interviewed through a brief screening questionnaire to a demographically balanced sample of 80,000 members of Synovate’s Consumer Mail Panel. Of the nearly half that responded, over 5% reported that one or more caregivers aged 8 to 18 lived in their household.

After responses were verified through re-screening, telephone interviews were conducted with 213 child caregivers and 250 noncaregivers with a comparable mix of ages and genders. The survey questionnaire was developed with consultation from an Advisory Group and was approved by the Towson University (MD) Institutional Review Board. Parents were asked for permission to interview their child, and were offered the opportunity to listen to the interview. Over a third (37%) listened to at least a portion of the child’s interview. The interviewer offered to provide a phone number for follow-up in case any child experienced distress during the interview (one child caregiver and one non-caregiver asked for the phone number.)

In the 18-minute interview, parents were first interviewed for about 6 minutes to learn about household composition and the caregiving situation. In addition, they were asked a series of questions about the child’s behavior and mood. Children were then interviewed for about 12 minutes.

The young caregiver report is available on the websites of the National Alliance for Caregiving ([www.caregiving.org](http://www.caregiving.org)) and the United Hospital Fund ([www.uhfny.org](http://www.uhfny.org)).

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