

Young Caregivers in the U.S.

Findings from a National Survey

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Acknowledgments

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Introduction

In the twenty-first century, almost everyone, it seems, has a family caregiving story to tell. As the population ages and as health care economics as well as consumer preference encourage community-based care of elderly, ill, and disabled persons, more and more relatives and friends find themselves providing most of that care in their own or their relative's home. Survey research has documented the broad spectrum of American adults who provide care; their ranks include men as well as women, young as well as middle-aged and elderly persons, immigrants and native-born citizens, and members of every ethnic and racial background, religion, family structure. Family caregiving today is truly an equal opportunity job.

But one part of the caregiving population has been overlooked — children. All the major U.S. surveys of caregivers include only people age 18 and over, partly because 18 is the age at which respondents can consent for themselves and partly because it is the norm to think of children as requiring care, not providing it. Yet caregiving influences children's lives and development, sometimes profoundly and in both positive and negative ways. In any group of health or social service professionals, there will be several who chose their careers because of their experiences as child caregivers, even though probably they were never identified in that way. Others carry into their adult lives resentment and anger at being saddled with caregiving responsibilities and emotions beyond their capacity to understand and manage.

Until this study no national prevalence studies or large-scale studies of the impact of caregiving on children had been conducted in the U.S. There are, to be sure, ample anecdotal evidence and case examples, as well as literary memoirs and selected studies of small populations such as children of parents with HIV/AIDS, alcoholism, or mental illness.

One study involving a self-administered survey of Palm Beach County, Florida, youth in grades six to twelve found that half of the children contribute to the care of someone who needed "special medical care." However, Palm Beach County's population composition is not typical of other areas because there is a higher than average percentage of older adults, young disabled adults, and people with HIV/AIDS.¹

A recent trend in caregiving has brought home the omission of children from the ranks of caregivers. Increasingly U.S. caregiving researchers and advocates are meeting with their counterparts in other countries. No matter how differently our health care and social service systems are organized, we find much in common in terms of caregiver needs and gaps in services. Yet there are some significant differences. In the case of child caregivers ("carers" in the British terminology), researchers and organizations in the United Kingdom, Australia, and New Zealand have made this group a priority since the 1990s. Recognition of child carers, for example, is included in the UK's National Carers Strategy (1999); and services such as support groups, recreation activities, and Web-based opportunities for young people to express themselves are now widely available across the country.

Participants at the Third International Conference on Family Care, held in Washington, DC, in October 2002, had the opportunity to hear young caregivers from Australia and New Zealand tell their own stories and describe how services designed with and for them had provided support when they needed it. That meeting was the stimulus for this report.

In September 2003 the U.S. Administration on Aging awarded a grant to the National Alliance on Caregiving, in collaboration with the United Hospital Fund's Families and Health Care Project, to conduct the first national survey of child caregivers in this country. In October 2003 the Fund held a two-day meeting in New York with invited researchers, practitioners, representatives of disease-specific organizations with child caregiver programs, and current and former young caregivers to discuss the

¹ Siskowski, C. "From Their Eyes....Family Health Situations Influence Students' Learning and Lives in Palm Beach County, Grades 6-12," A subreport of the "What Works" project, Dr. Bertrand Miller, project director, Palm Beach Atlantic University, West Palm Beach, FL. Available at: www.boca-respite.org/children.doc

issue. Three representatives from the UK also attended. Their perspective was particularly helpful in designing the survey and in thinking about future activities.

Attention to young carers in the UK has not been without controversy. Some members of disability advocacy groups contend that focusing on child carers tends to portray them as “victims” and their disabled parents as helpless or exploitative. As a result of this critique, current efforts in the UK are now more explicitly family-focused.

This report, the survey on which it is based, and its recommendations affirm the central role of parents as guardians of their children. Without compelling evidence to the contrary, parents are presumed to have their children's best interests at heart. It is important, nonetheless, to recognize that child caregivers who provide significant amounts of care have life experiences different from those of their noncaregiving peers, and need opportunities to explore both the positive and negative impacts. Health care and social service providers must be alert to the needs of vulnerable children and families without pitting parents' needs against those of their children, or vice versa.

Objectives and Methodology

This report presents the results of two studies conducted by Mathew Greenwald & Associates, Inc. on behalf of the National Alliance for Caregivers and the United Hospital Fund. The research had three main objectives:

1. To determine the prevalence of caregiving among children nationwide;
2. To learn what role children play in giving care; and
3. To learn how the caregiving role impacts the life of a child.

In the first study, designed to determine the prevalence of child caregiving, a random sample of 2,000 U.S. households were surveyed in a mailed omnibus study in September 2003. (Omnibus studies include questions on many different topics.) Respondents were asked whether any child 8 to 18 years of age in the household provides unpaid help or care to any person. It also 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” [see Appendix A for the questionnaire]. The definition of caregiving was broad but specific so that not all children who happen to live in a household where someone has an illness or disability would be defined as a caregiver.

The study, conducted by International Communications Research (ICR), included equal proportions of men and women, and results were weighted to provide nationally representative and projectable estimates of the adult population 18 years of age and older. Results were then post-stratified and balanced by key demographics such as age, sex, region, and education. The sampling error is plus or minus one to two percentage points.

In the second study, developed to learn about child caregivers’ roles and the impact their responsibilities have on them, a two-stage methodology was used. The first stage, to identify child caregivers to be interviewed, involved sending a brief screening questionnaire to a demographically balanced sample of 80,000 members of Synovate’s Consumer Mail Panel (CMP), which consists of over 600,000 households nationwide. Caregiving was defined broadly in the screener so that as many potential caregivers would be identified as possible. Of the nearly half that responded (49%), over 5% reported that one or more caregivers 8 to 18 years of age lived in their household.

The second stage confirmed the responses through re-screening, and then conducted telephone interviews with 213 child caregivers and 250 non-caregiving children with a comparable mix of ages and genders. All non-caregiving children lived in households where none of the children were caregivers. In the effort to ensure that the age and gender balance of the caregiver sample was representative of child caregivers, the child to be interviewed was selected randomly from all of the 8- to 18-year-old caregivers in the household. Initially, the non-caregivers to be interviewed were also selected randomly from among the 8- to 18-year-olds in the household. However, preliminary analyses showed the caregiving children were slightly older than randomly selected non-caregivers, so later non-caregiver interviews were conducted with the oldest child present. Upon completion of the interviews, weights were applied to make a slight adjustment in the age-gender balance of non-caregivers so it would match that of caregivers.

The survey questionnaire was developed with consultation from an Advisory Committee (see Acknowledgments section at the front of this report for names) and was approved by the Towson University Institutional Review Board. Parents were asked for permission to interview their child, and were offered the opportunity to listen to the interview. Over one-third of parents listened to at least a portion of the child’s interview (37%). The protocol included a phone number for KidPeace for follow-up in case any child experienced distress at any of the questions (one child caregiver and one noncaregiver asked for the phone number).

The telephone interview lasted 18 minutes. First the parents were interviewed for about 6 minutes, to learn about the household composition and the caregiving situation. In addition, parents were asked a series of questions that were drawn from the Behavior Problems Index, a 28-item series of questions for parents to report on their child's behavior.² This study used six questions that comprise the anxious-depressed subscale of the index as well as seven questions that make up the antisocial subscale. [The content of the questions and the method for creating the subscale scores are described in Section C, "Behavior Problems," in the detailed findings.] The children were then interviewed for about 12 minutes, during which they were asked about the way they spend time, their self-perceptions and moods, and their school work. In addition, caregivers were asked about their caregiving responsibilities.

Assuming that the panelists are equivalent to a random sample of U.S. residents, the margin of sampling error for findings relating to caregivers, at the 95% confidence level, is plus or minus 7 percentage points. For non-caregivers, the sampling error is plus or minus about 6 percentage points. Subgroup responses will have larger sampling error, depending on the size of the group.

Limitations of the Study

The limitations of the current study are related both to the data collection procedures and the topic in general. Prevalence estimates were based upon results of questions asked during an omnibus survey of individuals selected at random; these estimates have a margin of error related to both the sampling strategy and the topic. Adults who are cared for by children might be unwilling or unable to participate in a survey in general and/or unwilling to participate in a survey regarding their care specifically. And, of course, this strategy for estimated prevalence does not capture those who do not speak English, do not have a telephone, or who are unwilling to respond to surveys by phone.

The second phase of the study, the confirmation phase conducted by a mail screening, was also likely influenced by the nature of the research. Some respondents who are being cared for by children may be uncomfortable completing and returning the mail-in questionnaire used to identify households for the telephone interview. Similarly, the issues raised during the interviews conducted with the parents and children are likely to understate the effects of child caregiving on both the children and the parents. Children, particularly those whose parents listened in on the interview, may understate the effects on them personally of the care situation. And, finally, those households involved in the most difficult and intense care situations were likely not included in the study.

The findings of the study should be considered to be representative of households that include child caregiving *and* are willing to discuss this situation and not necessarily all households that contain a child caregiver. The prevalence rates should also be considered to be conservative estimates of this social phenomenon.

² Zill, N., [Behavior Problems Index Based on Parent Report](#). Washington, DC: Child Trends, 1990.

KEY FINDINGS

Prevalence of Child Caregivers

- Nationwide, there are approximately 1.3 to 1.4 million child caregivers who are between the ages of 8 and 18. This number is more than the total of students in grades 3-12 in New York City, Chicago, and the District of Columbia.
- Of the 28.4 million households that have a child 8 to 18 years of age living there, 3.2%, or 906,000 households, include a child caregiver.

Caregiver Characteristics

- Three in ten child caregivers are ages 8 to 11 (31%), and 38% are ages 12 to 15. The remaining 31% are ages 16 to 18.
- Child caregivers are evenly balanced by gender (male 49%, female 51%).
- Caregivers tend to live in households with lower incomes than do non-caregivers, and they are less likely than non-caregivers to have two-parent households (76% vs. 85%).

Care Recipient Characteristics

- Seven in ten child caregivers are caring for a parent or grandparent (72%). Of these, the care recipient is their mother (28%) or grandmother (31%). One in ten child caregivers is helping a sibling (11%). Caregivers in minority households are more likely to be caring for their mother (42%) than those in nonminority households (25%).
- Two-thirds of caregivers live in the same household as their care recipient (64%).
- The majority of the care recipients are in two age ranges: 40 to 59 (32%) and 60 to 79 (25%). Smaller percentages are aged 19 to 39 (15%) or 80 and older (19%), and 1 to 18 (9%).
- The most common care recipient conditions are Alzheimer's disease or dementia (18%); disease of the heart, lung, or kidneys (16%); arthritis (14%); and diabetes 14%).

Caregivers' Responsibilities

- 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 beds and chairs, toileting, and feeding. Nearly all help with instrumental activities of daily living (IADLs), such as shopping, household tasks, and meal preparation.
- Of the 14 caregiving responsibilities examined in this study, the two most common are keeping the care recipient company (96%) and helping with chores (85%). Next most common are helping with grocery shopping (65%) and meal preparation (63%).
- At least one-quarter of caregivers help with one or more of the following four additional caregiving responsibilities: getting in and out of beds and chairs (42%), getting around the neighborhood (35%), taking medicines (30%), and feeding (27%).
- One in six child caregivers (17%) helps the care recipient communicate with doctors or nurses, and 15% of those aged 12 and older help make calls and arrangements for other people to help the care recipient.
- Child caregivers are not providing care alone. At least three-quarters of the child caregivers who help with any given task say that someone else helps with it also.

- However, caregivers in minority households are much less likely than nonminorities to report that others help them with caregiving tasks, including chores (78% vs. 93%), meal preparation (59% vs. 90%), dressing (50% vs. 84%), and giving medicines (65% vs. 89%).
- Half of caregivers say they spend *a lot* of time helping to take care of their care recipient (49%).

How Caregiving Affects Children's Use of Time

- Similar proportions of caregivers and non-caregivers report engaging in leisure time activities such as watching television, doing other pastimes alone, playing with friends, and participating in organized activities.
- However, caregivers spend more time than non-caregivers doing household tasks, including sweeping, vacuuming, or dusting (caregivers 84% doing this *a little* or *a lot* vs. non-caregivers 72%), shopping for groceries (68% vs. 55%), doing laundry (57% vs. 48%), and making dinner (58% vs. 45%). Some of these differences may be partially due to the fact that so many caregivers help their care recipient with household chores.
- Caregivers, especially girls, are also more likely than non-caregivers to spend more time caring for siblings than non-caregivers do. Overall, 80% of the caregivers who have other children in the household take care of a sibling (other than the care recipient), compared to 64% of non-caregivers.
- Girls (21%) are twice as likely as boys (10%) to say that the care recipient confides in them, that is, tells them things they don't talk to anyone else about. Confiding is also more likely to occur in minority households (31% vs. 12%) and where caregiver and care recipient live in the same household (20% vs. 8%).

How Caregiving Affects Children's Behavior, Self Perceptions, and Feelings

Behavior Problems

- Child caregivers tend to show anxious or depressed behavior more than non-caregivers, according to parents' reports of their child's behavior.
 - 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 ages 8 to 11 (36% vs. 20%) and among those who are 12 to 18 years of age (23% vs. 14%).
 - In addition, the younger caregivers are more likely to complain that they feel worthless or inferior, at least *sometimes* (35% vs. 18%), and the 12- to 18-year-old caregivers are slightly more likely than non-caregivers of their age to have sudden changes in mood (61% vs. 51%).
- Further, a larger share of caregivers ages 12 to 18 behave antisocially than non-caregivers of the same age.
 - In particular, they are more likely than non-caregivers to have trouble getting along with teachers (27% vs. 14%), to bully or act mean towards others (24% vs. 9%), to be disobedient at school (20% vs. 13%; marginal difference), and to associate with kids who get in trouble (17% vs. 9%).

Self-Perceptions and Feelings

- Caregivers have marginally less time for themselves than non-caregivers; 38% say they have time for themselves *a lot*, compared to 47% of non-caregivers).

- Further, boy caregivers' self-expression is affected. They are twice as likely as boys who are not caregivers to feel that it is no use showing their feelings (26% vs. 11%).
- Positive effects of caregiving include caregivers' tendency to feel appreciated for help they give (64% feel this way *a lot* vs. 53% of non-caregivers). Caregivers are also less likely to feel people expect too much from them (12% *a lot* vs. 19%) or to feel angry about all they have to do (8% *a lot* vs. 13%).
- Overall, caregivers' feelings of self-esteem, sadness, loneliness, and fun are similar to those of non-caregivers. However, boy caregivers are more likely to feel sad than are boys who are not caregivers (52% vs. 38%).
- Other self-perceptions of caregivers, as well as their views on relationships with others, are similar to those of non-caregivers (e.g., their perceptions of whether grown-ups listen to their problems, whether they can depend on others, whether parents pay enough attention to them, feelings of productivity, perceived competency, fairness of amount of housework, and feelings of being grown up).
- In several areas, caregivers are similar to non-caregivers. For example, caregivers report their overall level of responsibility similarly to non-caregivers, even though they spend more time on household tasks and caregiving; over four in ten of each group feel they have *a lot* of responsibility (45% and 43%, respectively).
- Caregivers and non-caregivers report similar school problems such as being too worried to concentrate on school work *sometimes* or *a lot* (58% vs. 56%), missing turning in homework (41% vs. 36%), being absent from school (32% vs. 33%), being kept from school work by other responsibilities (31% vs. 32%), and falling asleep in class (19% vs. 22%).
- Nevertheless, some caregivers do report that their caregiving responsibilities have affected their school work or school activities. One in five say their caregiving has made them miss a school activity or an after-school activity (20%), 15% say it has kept them from doing school work, and 8% say it has made them miss homework.

Factors Influencing How Much Caregiving Affects the Child

The effects of caregiving on a child appear to be stronger when one of three factors is present: when the child performs one or more personal care tasks, when the child lives in the same household as the care recipient, and when the child lives in a minority household. The first two factors are interrelated, because caregivers who live with their care recipient are more likely than other caregivers to perform three of the five ADLs.

ADLs

- Caregivers who help with ADLs perceive themselves as having more responsibility than do non-ADL caregivers. Perhaps related, they are twice as likely to feel *a lot* that people expect too much from them (16% vs. 7%). They also tend to feel it is no use letting their feelings show more than do non-ADL caregivers (23% vs. 12% feel this way *a lot*) and to feel that they cannot depend on anyone else (49% vs. 31% at least *sometimes*).
- A larger share of these ADL caregivers than non-ADL caregivers exhibit sudden mood changes (70% vs. 48%).
- ADL caregivers report being absent from school (38% at least *sometimes*) more than do non-ADL caregivers (24%). They are also twice as likely as other caregivers to say that helping their care recipient has made them miss a school or after-school activity (25% vs. 12% at least *sometimes*).

Presence of Care Recipient in Household

- Among younger children (ages 8 to 11), caregivers' increased likelihood to show anxiety/depression and antisocial behavior is more pronounced when the care recipient and caregiver live in the same household. The most pronounced difference is in the frequency of being sad or depressed; 56% of those in the same household report feeling sad or depressed often or sometimes, compared to 19% not living in the same household.
- In co-residence situations, the caregiver spends more time giving care than when the caregiver lives apart from his/her care recipient. Further, co-residing caregivers are less likely than other caregivers to feel that they had a productive day (36% vs. 50%).
- Caregivers who co-reside with their care recipient report not submitting their homework assignments more often (47% at least *sometimes*) than other caregivers (29%).

Minority Status

- Among older child caregivers (ages 12 to 18), those in minority households tend to score higher, based on parental reports, than non-minorities on measures of anxiety/depression and antisocial behavior. Minority parents also report higher instances of their child bullying or being mean (46% vs. 20%) and disobeying at school (42% vs. 16%).
- The caregivers in minority households are also more likely than non-minorities to have felt sad in the past week (69% vs. 47% *sometimes* or *a lot*), and to report that they often feel it is no use letting their feelings show (33% vs. 15%).
- As noted, smaller proportions of minority caregivers report that someone else helps them with caregiving tasks. This may be part of the reason that they experience more negative effects of caregiving than do non-minorities.

Conclusions

This survey provides the first national data about child caregivers in the U.S. Many of the results are reassuring, in the sense that children engaged in caregiving are not usually doing it alone and are participating in the same educational and social activities as their noncaregiving peers. There are indications, however, that some children are experiencing distress that is manifested in behavioral and school problems and feelings of isolation and sadness. Boys in particular seem to have more difficulties than girls. Children in minority households, which have lower incomes, are also under particular stress and report less help in carrying out their tasks.

As a broad national survey, this report provides an outline but not the details. We need more information to fill in the picture to understand which characteristics of children, their families, and their environment potentially lead to problems and which support a positive outcome. For example, we suspect significant differences in the experiences of children caring for parents versus those caring for grandparents.

There is no single response that is appropriate for every child and every family. Nor is there a natural organizational "home" for the activities and services that might be helpful in different situations. Services for adult caregivers are not appropriate for children, nor do agencies that typically deal with adult caregivers have experience working with children. The healthcare system also lacks the means to detect problems in this population and intervene when necessary. Some services might be developed through organizations that serve the parent (or other family member who requires assistance); others through youth-serving organizations; schools; or community agencies. Since very few services exist at present, there is a wide range of possibilities to explore and collaborations to develop. Those services that do exist are generally found in disease organizations like Cancer Care and the MS Society that serve individuals with these diseases and their families. Al-Anon/Alateen, a branch of Alcoholics Anonymous, offers weekly support groups for adolescents (average age 14) with family members, usually their parent or stepparent, who abuse alcohol.

Some principles to guide the development of services include:

- The central role of the family, however it is structured;
- Participation of young people themselves in developing services;
- Understanding the needs and abilities of children of different ages and developmental levels;
- Recognizing and supporting the contribution of children's caregiving to their families;
- Recognizing the cultural significance of caregiving in different families.

The wide range of services available in the UK, Australia, and New Zealand offer many possibilities for demonstration projects, such as support groups, Internet chat groups, writing assignments, art and drama workshops, recreational activities, and activities that include the whole family. At the same time, these programs must be evaluated for their appropriateness in the U.S. and adapted to a variety of situations.

Many research, practice, and policy questions remain unanswered.

- What is the best way to distinguish child caregiving from the ordinary chores that children in most families are expected to perform?
- Are there some caregiving tasks or levels of responsibilities that are inappropriate for children?
- What are the special needs of child caregivers in households where they act as interpreters for care recipients in their dealings with the health care system?
- What are the special needs of child caregivers when the care recipient has a mental illness or is addicted to drugs or alcohol?

- Do support groups work best when children in different kinds of caregiving situations are brought together or when the care recipient's condition is the same?
- How can the Internet be utilized to encourage communication among child caregivers? Between child caregivers and professionals?
- How can teachers and schools recognize children who need assistance and provide referrals without violating parental rights?
- As child caregivers age beyond adolescence, how can educational, social, and career opportunities be encouraged in the context of caregiving?

One possible next step is a consensus conference to build a research, practice, and policy agenda that includes child caregivers, their parents and other family members, organizational representatives, government agencies, health care and social service professionals.

DETAILED FINDINGS

A. Prevalence of Caregiving

About one in four households, equivalent to 28.4 million households in 2002, has a child 8 to 18 years of age living there (26%). The omnibus survey of 2,000 households shows that 3.2% of those households with children, or 906,000 households, include a child caregiver. A caregiver was defined as anyone who provides unpaid help or care to anyone in the household or any relative, whether or not the relative lives with the caregiver. The care was described as possibly including help with personal needs, meals, household chores, shopping, paperwork, medication, getting around, or visiting regularly to see how the care receiver is doing

The omnibus study also showed there are 1.44 caregivers ages 8 to 18 in each child caregiver's household, on average.³ A similar average number of child caregivers per household (1.55) was also found in the interviews of 213 caregivers. Caregiving was defined more stringently in this phase of the study, however. A child caregiver was defined as anyone aged 8 to 18 living in the household who provides unpaid help or care to any person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled, or mentally ill. In addition, to qualify as a caregiver, a parent had to report that the child helps the care receiver with one or more of the following tasks:

- Household chores or meal preparation
- Dressing or feeding
- Taking medicine or talking to doctors and nurses
- Keeping him/her company, providing emotional support
- Shopping
- Paperwork, bills, or arranging outside services
- Moving around the house, getting around the community
- Bathing or using the bathroom

Multiplying the total number of households with child caregivers (906,000) by the average number of child caregivers per household (1.44 to 1.55), leads to an estimate of 1.3 to 1.4 million child caregivers nationwide.

³ This average is based on a very small sample of child caregiver households (n=18).

B. Caregiving Situation

Care Receiver Characteristics

Seven in ten child caregivers are caring for a parent or grandparent (72%) [see Table 1]. Specifically, one-third are caring for a parent (34%), primarily their mother (28%). Slightly more than one-third take care of a grandparent (38%); again the grandmother is the care receiver far more often (31%) than the grandfather (7%). One in ten child caregivers are giving care to a sibling (11%), with about half of these helping a sister (6%) and half helping a brother (6%). Fewer than one in ten are caregivers for other relatives (9%)—mainly aunts, uncles, and great grandparents—or non-relatives (8%).

- Caregivers in minority households are more likely to be caring for their mother (42%) than those in non-minority households (25%).

Overall, nearly three-quarters of the care receivers are female (73%). Caregivers are evenly split as to whether they care for someone of the same sex (51%) or opposite sex (48%). However, female caregivers are much more likely to have a same-sex care receiver (74%) than are male caregivers (27%).

The ages of care receivers correspond to the fact that most are parents or grandparents of the caregiver. Four in ten of the care receivers are age 60 or older (44%) and one-third are ages 40 to 59 (32%). Fifteen percent are ages 19 to 39, and 9% are ages 1 to 18.

Two-thirds of caregivers live in the same household as the care receiver (64%).

Over two-thirds of the care receivers can walk without help from another person (69%). Eighteen percent walk with help from another person, and 11% cannot walk but use a wheelchair. Only 1% of the care receivers are bedridden.

- Younger caregivers are more likely than older ones to care for someone who can walk without help (80% of 8- to 11-year-olds vs. 60% of 16- to 18-year-olds).

Table 1
Care Receiver Characteristics

(n=213)	Percent [†]
<u>Relationship to Caregiver</u>	
Parent or step-parent (net)	34
<i>Mother</i>	28
<i>Father</i>	6
Grandparent (net)	38
<i>Grandmother</i>	31
<i>Grandfather</i>	7
Sibling or step-sibling (net)	11
<i>Sister</i>	6
<i>Brother</i>	6
Aunt or uncle	3
Other relative	6
Other non-relative	8
<u>Gender</u>	
Male	26
Female	73
Not reported	1
<u>Gender—Care Receiver vs. Caregiver</u>	
Same sex as caregiver	51
Opposite sex as caregiver	48
Not reported	1
<u>Age</u>	
1 to 18	9
19 to 39	15
40 to 59	32
60 to 79	25
80 or older	19
<i>Average</i>	54
<u>Where Living</u>	
Lives in household	64
Does not live in household	36
<u>Mobility</u>	
Can walk without help from another person	69
Can walk with help from a person	18
Cannot walk, but can use a wheelchair	11
Bedridden	1
Don't know	*

[†]Rounding may cause discrepancies between totals and the sums of subsets.

* Less than 0.5%

The most common conditions for which the care receiver needs assistance are Alzheimer's or dementia (18%; see Table 2 and note below it); heart, lung, or kidney disease (16%); arthritis (14%); and diabetes (14%). Roughly one in ten respondents report functional decline, sometimes saying the care receiver cannot do as much as s/he used to due to age (11%). Back problems and bone or joint problems are each cited by 7%, followed by paralysis or spine injury (5%), stroke (5%), autoimmune diseases such as fibromyalgia (4%), cancer (4%), and mental retardation (4%). A wide range of other conditions is present in smaller percentages of care receivers.

Table 2
Condition Needing Care

(n=213)	Percent		Percent
Alzheimer's, dementia †	18	Amputation	1
Heart, lung, kidney disease	16	Autism	1
Arthritis	14	Circulation, vascular disease	1
Diabetes	14	Crohn's Disease	1
Functional decline, old age	11	Deafness, hearing impairment	1
Back	7	Epilepsy, seizures	1
Bone or joint fractures or problems	7	High blood pressure	1
Paralysis, spine injury	5	Mental illness	1
Stroke, TIA	5	Wounds	1
Autoimmune syndrome, fibromyalgia	4	Catheter	*
Cancer	4	HIV/AIDS	*
Mental retardation, Down's Syndrome	4	Legs, feet, walking	*
Depression, mental health	3	Memory problems	*
Multiple Sclerosis	3	Parkinson's Disease	*
Blindness, vision impairment	2	Other	13
Cerebral Palsy	2	Don't know	2
Pain, headaches	2	Refused	*
Brain/head injury	2		

† The presence of this condition was determined by asking about the care receiver's situation in both an unaided question and an aided question. The presence of all other conditions was gathered only in an unaided question.

* Less than 0.5%

Household Characteristics

There is a tendency for caregivers to have more children in their households than non-caregivers [see Table 3]. Equal proportions of caregivers and non-caregivers are the only child age 18 or younger in their household (35% and 33%, respectively). But 14% of caregivers say there are four or more children in their household, compared to 6% of non-caregivers. By contrast, only one-third of caregivers say there are two children in the household, compared to four in ten non-caregivers who do (31% vs. 40%). One-fifth of each say there are three children (20%).

For fewer than one-fifth of caregivers, the only other children in the household are under the age of seven (17%). One-third live with other 8- to 18-year-olds, but no younger children (32%). Sixteen percent live in households with children in both age groups. Among non-caregivers, the age mix of children in the household is quite similar.

The majority of child caregivers (61%) are the only 8- to 18-year-olds in their household who provide care to someone who is elderly, frail, disabled, or mentally ill. However, one-quarter of parents in caregivers' households report there are two child caregivers (28%), and 11% say there are three or more. As mentioned earlier, in child caregiver households, an average of 1.55 children ages 8 to 18 are caregivers.

Parents of non-caregivers are more likely than caregivers' parents to report that they have a spouse or partner living in the household (85% vs. 76%).

- Looking solely at caregivers, the presence of a spouse or partner is less common among racial or ethnic minorities (56%) than non-minorities (80%).

In eight in ten caregiving households, the parent who is on the panel is a white, non-minority (83%) and the remaining 17% are minorities. In non-caregiving households, 88% of the panelists are non-minorities and 12% are minorities.

Caregivers' live in households with lower incomes than do non-caregivers. Four in ten caregivers (39%) live in households with at least \$50,000 in income, whereas 63% of non-caregivers do.

Table 3
Household Characteristics

	<u>Percent Caregivers</u> (n=213)	<u>Percent Non-Caregivers</u> (n=250)
<u>Total Number of Children in Household (including respondent)</u>		
One	35	33
Two	31	40*
Three	20	20
Four or more	14*	6
<u>Age Groups of Other Children in Household</u>		
No other children under age 18	35	33
Only other children are 0- to 7-year-olds	17	18
Only other children are 8- to 18-year-olds	32	38
There are other children 0 to 7 and 8 to 18	16	10
<u>Number of 8- to 18-Year-Olds in Household (including respondent)</u>		
One	52	52
Two	30	37
Three or more	18	12
<u>Number of 0- to 7-Year-Olds in Household</u>		
None	67	71
One	22	20
Two	6	7
Three or more	5	2
<u>Number of Children Providing Care</u>		
None	--	100
One	61	--
Two	28	--
Three or more	11	--
<u>Presence of Parent's Spouse/Partner</u>		
Spouse/partner lives in household	76	85*
No spouse/partner lives in household	24	15
<u>Minority Status</u>		
Non-minority	83	88
Minority	17	12
<u>Household Income</u>		
Less than \$25,000	32*	12
\$25,000 to \$49,999	28	26
\$50,000 to \$74,999	15	25*
\$75,000 or higher	24	37*

* Significantly higher than counterparts (at .95 level)

Three in ten child caregivers between the ages of 8 and 18 are ages 8 to 11 (31%), and almost four in ten are ages 12 to 15 (38%) [see Table 4]. The remaining 31% are between the ages of 16 and 18. There is an even balance of males and females.

As discussed in the introduction, non-caregivers were purposefully weighted so that their age and gender balance would match that of caregivers.

Table 4
Respondent Characteristics

	<u>Percent Caregivers</u> (n=213)	<u>Percent Non-Caregivers</u> (n=250)
<u>Age of Child</u>		
8 to 11 (net)	31	31
8	4	6
9	6	9
10	12	7
11	9	9
12 to 15 (net)	38	38
12	9	8
13	11	8
14	8	10
15	10	12
16 to 18 (net)	31	31
16	14	11
17	9	12
18	8	8
<u>Gender of Child</u>		
Male	49	49
Female	51	51

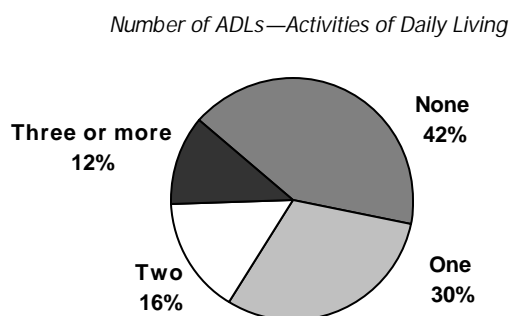
Caregiving Responsibilities

ADLs—Activities of Daily Living

About six in ten child caregivers help their care receiver with at least one activity of daily living (ADL) (58%) [see Figure 1]. ADLs include bathing, dressing, getting in and out of beds and chairs, using the bathroom or diapers, and feeding. Specifically, 30% of child caregivers help with one ADL, 16% help with two, and 12% help with three or more.

Figure 1
Number of ADLs Performed by Child Caregiver

(n=212 caregivers)



IADLs—Instrumental Activities of Daily Living

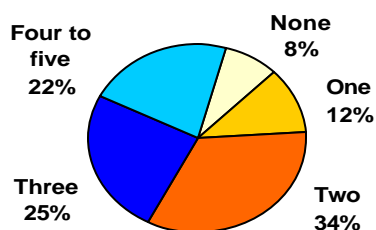
Nearly all child caregivers help with at least one instrumental activity of daily living. (IADL) [see Figure 2]. These include household chores, grocery shopping, preparing meals, helping with medications, helping get around the community, and for caregivers ages 12 and older, paperwork or bill paying. In fact, among younger caregivers ages 8 to 11, more than one in five (22%) help with at least four of the five IADLs they were asked about. Among the older caregivers, 38% help with at least four of six IADLs.

Figure 2
Number of IADLs Performed by Child Caregiver

Number of IADLs—Instrumental Activities of Daily Living

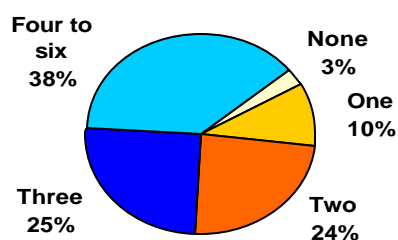
Out of 5 total IADLs
Among Younger Caregivers (8-11 years old)

(n=65)



Out of 6 total IADLs (includes bill paying or paperwork)
Among Older Caregivers (12+ years old)

(n=147)



Specific Caregiving Responsibilities

The most common caregiving activity is to keep the care receiver company (96%) [see Figure 3]. Three IADLs are the next most common activities; 85% of child caregivers help their care receiver with household chores, followed by more than six in ten helping with grocery shopping (65%) and preparing meals (63%). Continuing to examine IADLs, roughly three in ten help their care receiver get around the neighborhood or city (35%) or help with medications (30%). Among caregivers age 12 and older, 17% help their caregiver with paperwork or bill paying.

The ADL performed by the largest proportion of child caregivers is helping the receiver get in and out of beds and chairs; 42% of child caregivers help with this. One-quarter help feed their care receiver (27%), and 19% help the person get dressed. Fewer than one in ten help the care receiver with toileting (8%) or bathing (8%).

One in six child caregivers help their care receiver communicate with doctors or nurses (17%), an activity not typically grouped with ADLs or IADLs. In addition, 15% of those who are ages 12 or older help make calls and arrangements for other people to help the care receiver.

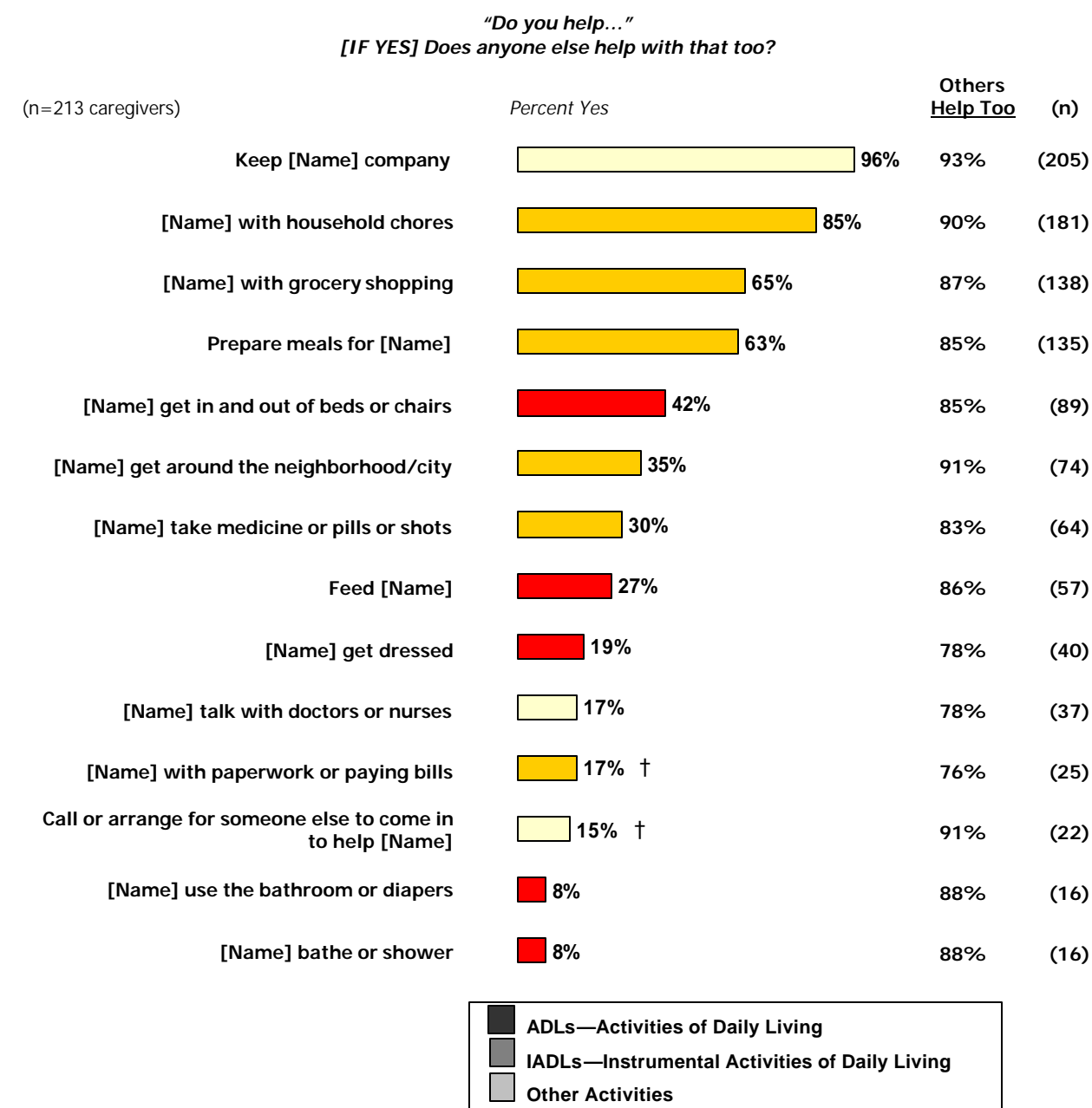
- For all but one of the 14 caregiving activities, boys and girls are equally likely to help their care receiver. The one exception is making arrangements for outside help; girls are twice as likely as boys to be involved in this (21% vs. 9%).
- Three of the IADLs—preparing meals, getting around the city, and helping with medicines—are more commonly performed by caregivers who also help with ADLs. For example, 44% of those who help with ADLs also help the care receiver with medicines or shots, compared to 10% of caregivers who do not help with ADLs. In addition, facilitating communication with health personnel is associated with ADL caregivers (27%) more than non-ADL caregivers (4%).
- Three of the ADLs are more common for caregivers whose care receiver lives in the same household—dressing (same household 26% vs. different household 7%), bathing (10% vs. 3%), and toileting (10% vs. 3%). In addition, meal preparation shows the same pattern (71% vs. 50%).
- The prevalence of helping with meal preparation and getting around the city increases with the age of the caregiver. Similarly, 16- to 18-year-olds are more likely to help with paperwork (26%) than are 12- to 15-year-olds (10%).

Sharing of Responsibilities

For each of the caregiving tasks above, at least three-quarters of the caregivers who perform the task say someone else helps with it too. The responsibilities with which child caregivers are least likely to be helped by others are dressing the care receiver (78% say someone helps), talking with doctors and nurses (78%), and handling paperwork or bills (76%).

- Caregivers in minority households are much less likely than non-minorities to report that others help them with caregiving tasks, including chores (78% of minorities who help their care receiver with this say others help vs. 93% of non-minorities), meal preparation (59% vs. 90%), dressing (50% vs. 84%), and giving medicines (65% vs. 89%).

Figure 3
Caregiving Responsibilities



† Among 12- to 18-year-old caregivers (n=147)

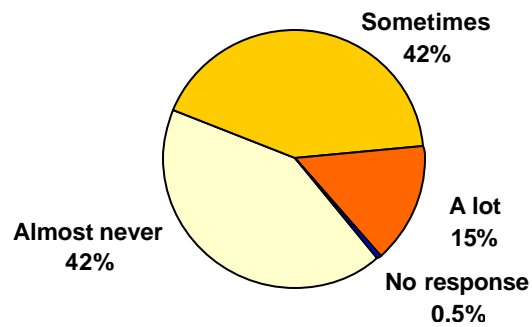
A majority of caregivers say their care receiver confides in them at least *sometimes*, with 15% saying this occurs *a lot*, and 42% saying it does *sometimes* [see Figure 4].

- Girls are twice as likely as boys to say they are confidants for their care receivers *a lot* (21% vs. 10%).
- Confiding is also more likely to happen in situations where the caregiver and care receiver live in the same household (20% vs. 8% when they live separately) and in minority households (31% vs. 12% for non-minorities).

Figure 4
Frequency of Care Receiver Confiding in Child Caregiver

“How often does [NAME] confide in you? That means talking to you about things that s/he doesn’t talk to anyone else about.”

(n=213 caregivers)



C. Behavior Problems

Both younger (8 to 11 years old) and older (12 to 18 years old) child caregivers are more likely to show anxious or depressed behavior than non-caregivers, and older caregivers are also more likely to behave antisocially, according to their parents.

These findings are based on answers to questions that were drawn from the Behavior Problems Index, a series of questions for parent report of child behavior developed by Nicholas Zill and James L. Peterson.

- The anxious-depressed subscale is made up of six questions that assess sudden mood changes, fearfulness or anxiety, sadness, feelings that no one loves the child, and feelings of worthlessness.
- The antisocial subscale includes seven questions about cheating or lying, feeling sorry about misbehavior, meanness, disobedience, destructive behavior, and trouble getting along with teachers.

The subscale scores count one point for each item that is *often* or *sometimes* true for the child in the past three months and zero points for each question that is *not* true. Because some of the Behavior Problems Index questions are designed to be administered only to those under the age of 12, and others are intended just for those ages 12 or older, these two age groups are analyzed separately.

Younger Children—8 to 11 Years Old

Caregivers 8 to 11 years old have, on average, higher scores on the anxious-depressed scale (2.15) than do non-caregivers of the same ages (1.56) [see Table 5]. This difference is largely driven by boys, with young male caregivers showing notably higher anxiety/depression ratings (2.32) than young male non-caregivers (1.39).

Table 5
Behavior Problems Index—Scales for 8- to 11-Year-Olds

	8- to 11-Year-Old <u>Caregivers</u>	8- to 11-Year-Old <u>Non-Caregivers</u>	Gender <u>Interaction</u>
<u>Anxious-Depressed Scale</u>	(n=65)	(n=93)	
Mean	2.15 *	1.56	X
Std Dev	1.66	1.34	
<u>Antisocial Scale</u>	(n=64)	(n=94)	
Mean	1.33	1.41	--
Std Dev	1.30	1.37	

* Significantly higher than non-caregivers (at .95 level)

Underlying the overall difference between these young caregivers and non-caregivers is the finding that the caregivers are much more likely than non-caregivers to feel, at least some of the time, that no one loves them (36% vs. 20%) and that they are worthless or inferior (35% vs. 18%) [see Figure 5].

Differences between caregivers and non-caregivers in mood changes, fearfulness or anxiety, and sadness are not significant, but directionally do contribute to the significant differences in their overall anxious-depressed scale scores. Specifically, 58% of 8- to 11-year-old caregivers have sudden changes in moods at least occasionally, compared to 49% of non-caregivers of the same age; 44% of young caregivers are sometimes too fearful or anxious, compared to 35% of non-caregivers; and parents indicate that 41% of young caregivers are sometimes unhappy, sad or depressed compared to 36% of non-caregivers. On the mood change dimension, the difference between caregivers and non-caregivers is significant for boys (64% vs. 39%) but not apparent among girls (53% vs. 55%).

None of the individual questions about antisocial behavior show differences between young children who give care and those who do not. Roughly four in ten of both young caregivers (38%) and young non-caregivers (44%) cheat or tell lies *sometimes* or *often*, and just over one-third of each group do not seem to feel sorry after misbehaving, at least *sometimes* (36% each). Frequency of bullying behavior is similar (caregivers 27% vs. non-caregivers 19%), as is the prevalence of disobedience at school (12% vs. 20%), breaking things on purpose (11% vs. 12%), and trouble getting along with teachers (9% vs. 10%).

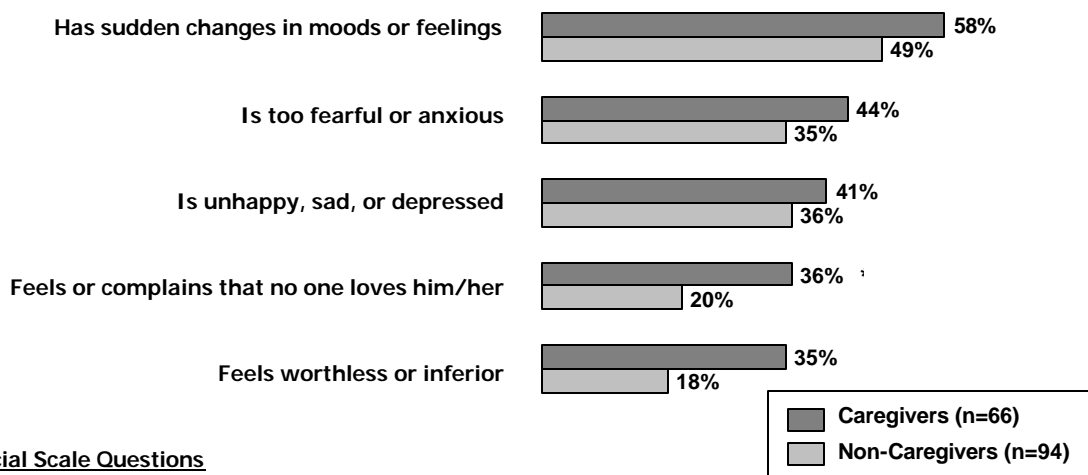
- Scores for both the anxious-depressed scale and the antisocial scale are higher when the caregiver and care receiver live in the same household. Caregivers who live with the receiver score an average of 2.54 on the anxious-depressed scale compared to 1.58 for others, with a difference in the frequency of being sad or depressed (56% vs. 19% *sometimes* or *often*). On the antisocial scale, those who co-reside score 1.66, on average, compared to 0.85 for those who live separately. The incidence of cheating or lying is the most significant driver of this difference (49% vs. 22% *sometimes* or *often*).

Figure 5
Behavior Problems Index— Individual Questions for 8- to 11-Year-Olds

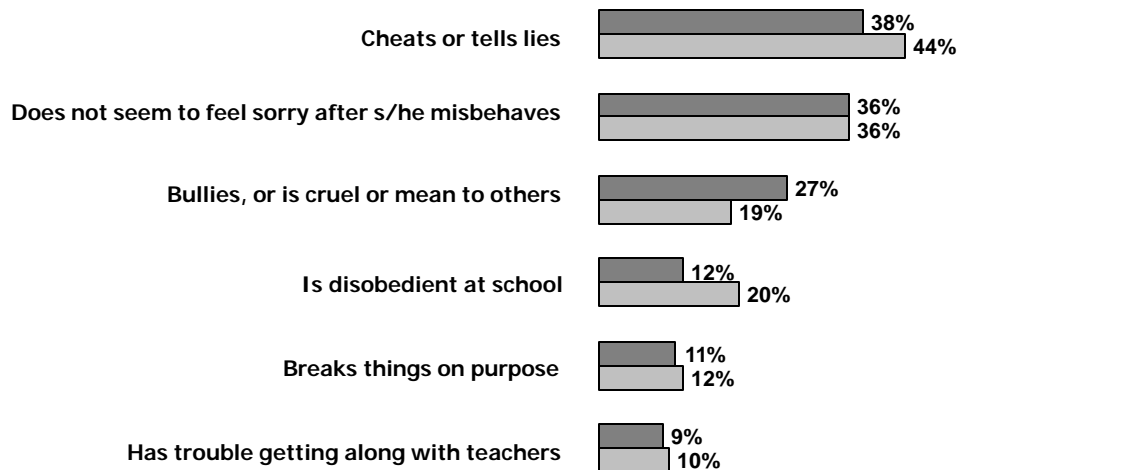
"In the past three months, has that been often true, sometimes true, or not true of [CHILD'S NAME]?"

Anxious-Depressed Scale Questions

Percent Sometimes or Often True



Antisocial Scale Questions



* Significantly higher than non-caregivers (at .95 level)

Older Children—12 to 18 Years Old

Among the older children, ages 12 to 18, the tendency for caregivers to be more anxious or depressed is slight, with caregivers scoring an average of 2.51 on the scale compared to 2.17 for non-caregivers [see Table 6]. These older child caregivers are also much more likely than non-caregivers of the same age to engage in antisocial behaviors (with average scale scores of 1.60 vs. 1.06).

- Interestingly, however, the difference between caregivers and non-caregivers in the antisocial scores is driven entirely by 12- to 15-year-olds, among whom caregivers score 2.02 compared to 1.03 for non-caregivers. The 16- to 18-year-old caregivers and non-caregivers have virtually identical average scores on that scale. Similarly, on the anxious-depressed scale, there are stronger differences between caregivers and non-caregivers among the 12- to 15-year-olds, with an average score of 2.79 for caregivers compared to 2.36 for non-caregivers of the same age.

Table 6
Behavior Problems Index—Scales for 12- to 18-Year-Olds

	12- to 18-Year-Old Caregivers	12- to 18-Year-Old Non-Caregivers	Gender Interaction
<u>Anxious-Depressed Scale</u>	(n=146)	(n=154)	
Mean	2.51 **	2.17	--
Std Dev	1.86	1.75	
<u>Antisocial Scale</u>	(n=146)	(n=156)	
Mean	1.60 *	1.06	--
Std Dev	1.72	1.37	

* Significantly higher than non-caregivers (at .95 level)

** Significantly higher than non-caregivers (at .90 level)

The 12- to 18-year-old caregivers' anxiety and depression are exemplified by their slightly increased tendency to have sudden changes in mood or feelings (61% vs. 51% of non-caregivers) and their increased likelihood of feeling that no one loves them (23% vs. 14%) [see Figure 6]. The difference in mood changes is much stronger among boys (58% vs. 44%) than girls (63% vs. 59%). By contrast, girls who give care are more likely to be fearful or anxious than are female non-caregivers (42% vs. 26%), but there is no parallel difference among boys. Although there are no significant differences between older child caregivers and non-caregivers on sadness and feelings of worthlessness, modest differences on these dimensions do contribute directionally to the difference in their overall anxious-depressed scale scores.

The 12- to 18-year-old caregivers' higher likelihood for antisocial behavior is shown in four particular behaviors: bullying, cruelty, meanness; trouble getting along with teachers; disobedience at school; and hanging out with kids who get in trouble. Both boys and girls who give care are more than twice as likely as non-caregivers to bully others, or to be cruel or mean (overall 24% vs. 9% of non-caregivers). In addition, both boys and girls who give care are more likely to have trouble getting along with teachers (overall 27% vs. 14%), although this behavior is more prevalent among boys, regardless of whether or not they give care. Differences between older child caregivers and non-caregivers on feeling sorry after misbehaving and cheating/lying are not significant, but do contribute to the overall difference in their antisocial scale scores.

Although, overall, caregivers 12 to 18 years old are slightly more likely than non-caregivers to be disobedient at school (overall 20% vs. 13%), this difference is apparent only among boys (32% vs. 20%).

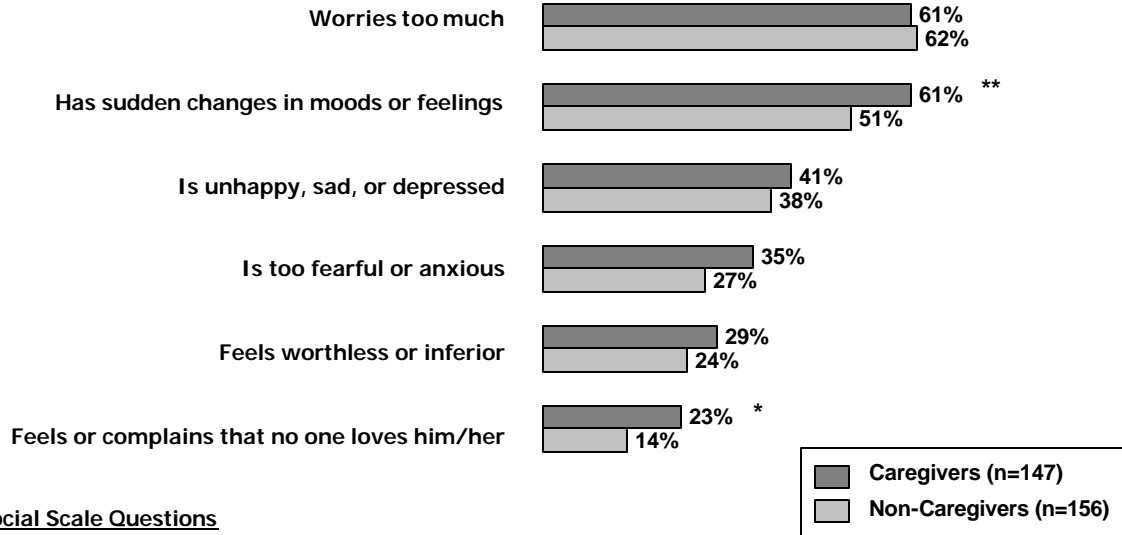
- As mentioned above, 12- to 15-year-old caregivers have higher average scores on the antisocial scale than do non-caregivers in that age span. In fact, they are more likely than non-caregivers to exhibit four of the six antisocial behaviors (trouble getting along with teachers, bullying, disobedience at school, hanging out with kids who get in trouble). No such difference is seen between 16- to 18-year-old caregivers and non-caregivers.
- Caregivers in minority households tend to score higher than non-minorities on both the anxious-depressed scale (average of 3.21 vs. 2.38) and the antisocial scale (2.50 vs. 1.43). Contributing to the difference in the anxious-depression scores is an increased frequency of minority parents reporting their child is too fearful or anxious (54% vs. 31% *sometimes* or *often*). Underlying the antisocial scale differences are increased reports by minority parents of their child bullying or being mean (46% vs. 20%), and disobeying at school (42% vs. 16%).
- Child caregivers who help with ADLs are more likely than those who help their receiver only in other ways to exhibit sudden changes in moods or feelings, according to their parents (70% vs. 48% of those who do not help with ADLs).

Figure 6
Behavior Problems Index— Individual Questions for 12- to 18-Year-Olds

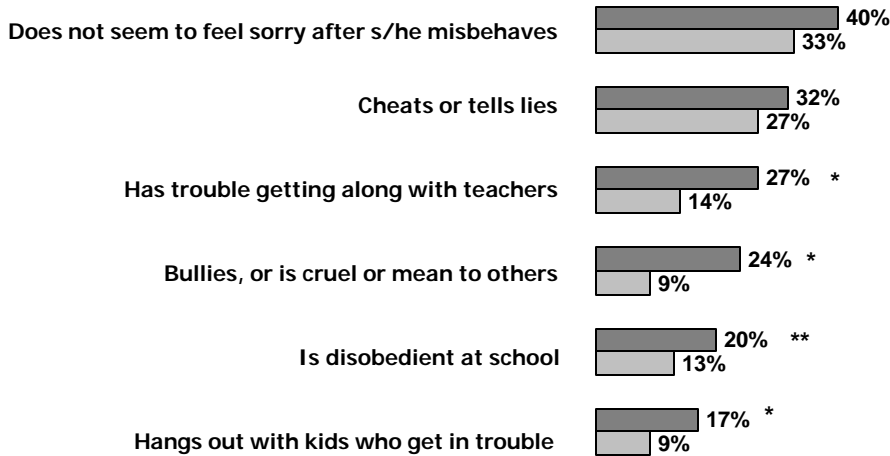
"In the past three months, has that been often true, sometimes true, or not true of [CHILD'S NAME]?"

Anxious-Depressed Scale Questions

Percent Sometimes or Often True



Antisocial Scale Questions



* Significantly higher than non-caregivers (at .95 level)
 ** Significantly higher than non-caregivers (at .90 level)

D. How Time Is Spent

Caregiving

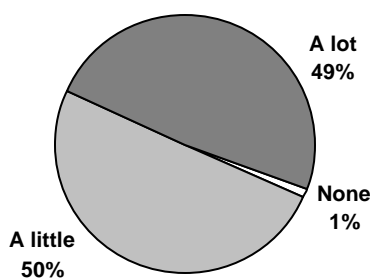
Half of child caregivers say, in a normal week, they spend *a lot* of time helping to take care of their care receiver, and half say they spend *a little* time doing so [see Figure 7].

- Those who help their care receiver with activities of daily living are more likely than others to say they spend *a lot* of time giving care (57% vs. 39%).
- When the care receiver lives in the household, the caregiver is also more likely to spend *a lot* of time giving care (55% vs. 37% for caregivers whose receiver lives elsewhere).

Figure 7
Amount of Time Spent Giving Care

"In a normal week, how much time do you spend helping take care of [name]?"

(n=213 caregivers)



Household Tasks and Leisure

Child caregivers spend more time than non-caregivers doing household tasks. In particular, they are more likely to spend at least *a little* time sweeping, vacuuming, or dusting (caregivers 84% vs. non-caregivers 72%), shopping for groceries (68% vs. 55%), doing laundry (57% vs. 48%), and making dinner (58% vs. 45%) [see Figure 8]. Caregivers and non-caregivers are equally likely to spend at least *a little* time washing dishes (63% vs. 56%, respectively).

The tendency for caregivers to spend more time doing laundry is evident only among girls (caregivers 64% vs. non-caregivers 49% spending *a little* or *a lot* of time in this activity).

- The difference between caregivers and non-caregivers in shopping for groceries is attributable to those who are over the age of 12. Prior to that age, there is no difference in the amount of time caregivers and non-caregivers spend on this task. Older caregivers (12+) are also slightly more likely to wash dishes than non-caregivers who are 12 or older.

Nearly all caregivers and non-caregivers report they spend at least *a little* time in leisure activities such as hanging out with friends, watching television, or by themselves doing other things they like (at least 95% of caregivers and non-caregivers report doing each). In addition, seven in ten caregivers and non-caregivers (72% each) participate in organized after-school or weekend activities including teams, clubs, scouting, lessons, and so on. Nine in ten spend some time doing homework (caregivers 91%, non-caregivers 94%).

- Among children ages 16 to 18, caregivers spend less time by themselves doing things they like and participating in organized activities. While about three in ten 16- to 18-year-old non-caregivers say they spend time by themselves *a lot* (32%) or participate in organized activities (29%), over four in ten non-caregivers that age engage in those activities (48% and 43%, respectively).

Overall, roughly equal proportions of caregivers and non-caregivers who are at least 12 years old spend time working at a job. But underneath this finding are contrasting findings for boys and girls. Four in ten boys who are caregivers work at a job (42%) compared to only 25% of non-caregivers. Among girls, a smaller proportion of caregivers (27%) than non-caregivers (37%) work, although this difference is not significant.

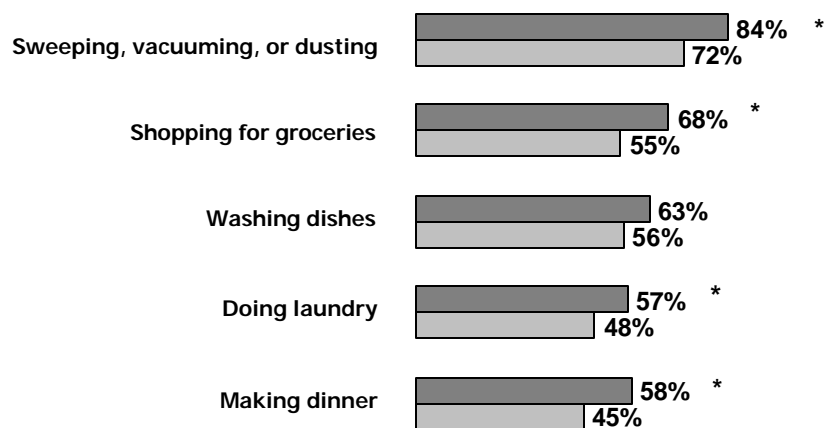
It is more common for child caregivers to shoulder responsibilities for sibling care than for non-caregivers to do so; 80% of caregivers who have other children in the household take care of a sibling (other than any child who is the care receiver), compared to 64% of non-caregivers. This difference is stronger for girls (caregivers 80% vs. non-caregivers 58%) than it is for boys (79% vs. 71%). Caregivers' increased childcare responsibilities may be due, in part, to the larger number of children in their households.

Figure 8
How Time Is Spent

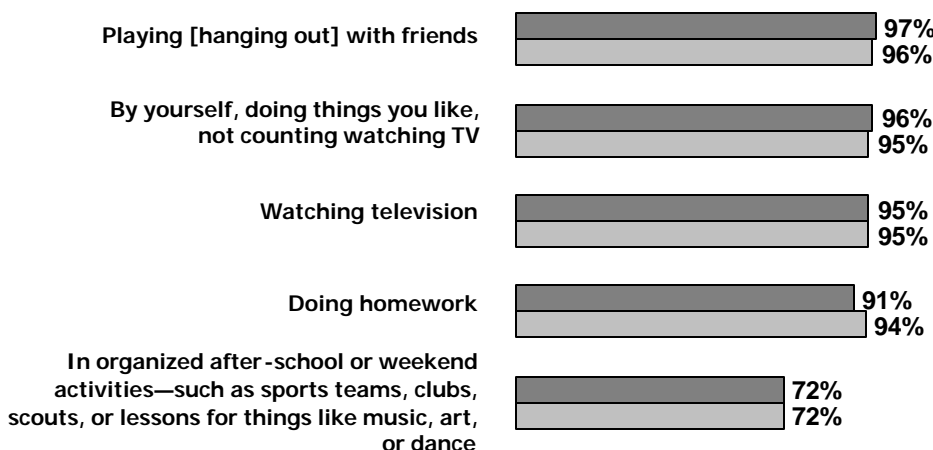
"In a normal week, how much time do you spend..."

Household Tasks

Percent a Little or a Lot

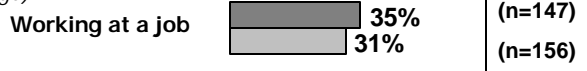


Leisure & Homework



Working at a Job

(Among those 12+ years of age)



Caring for Siblings

(Among those with other children in the household, in addition to the care receiver if caregiver is caring for a sibling)



* Significantly higher than non-caregivers (at .95 level)

Level of Responsibility

Even though child caregivers have more household and caregiving responsibilities, their perception of their overall level of responsibility is similar to that of non-caregivers [see Table 7]. Over four in ten of each feels they have *a lot* of responsibility (45% and 43%, respectively), and about half feel they have *some* responsibility (52% and 53%). Further, the frequency with which caregivers and non-caregivers report they have to miss fun activities because of their responsibilities is similar. Roughly one in ten caregivers (13%) and non-caregivers (10%) say this happens *a lot*, roughly six in ten say it occurs *sometimes* (caregivers 60%, non-caregivers 66%), and about one-quarter report it *almost never* happens (27%, 25%).

- Child caregivers who help with ADLs see themselves as having more responsibility than do caregivers who do not help with ADLs; 51% report having *a lot* of responsibility compared to 36% of non-ADL caregivers.

Table 7
Level of Responsibility

	<u>Caregivers</u> (n=213)	<u>Non-Caregivers</u> (n=250)
<i>How much responsibility do you think you have overall?</i>		
A lot	45%	43%
Some	52	53
Almost none	3	4
<i>How often do you have to skip a fun activity because you have more important responsibilities?</i>		
A lot	13%	10%
Sometimes	60	66
Almost never	27	25

E. Mood, Self-Perception, Outlook

Mood in the Past Week

Overall, caregivers' feelings of self-esteem, sadness, loneliness, and their experience of fun are not appreciably different from those of non-caregivers [see Table 8]. However, just among boys, a larger share of caregivers say they were sad in the past week *sometimes* or *a lot* (52%) than non-caregivers (38%).

- Caregivers in minority households are more likely to have felt sad in the past week *sometimes* or *a lot* (69%) than are non-minorities (47%).

Table 8
Mood in the Past Week

		<i>"In the past week, how often have you..."</i>	
		<u>Caregivers</u>	<u>Non-Caregivers</u>
		(n=213)	(n=250)
Had fun	A lot	72%	72%
	Sometimes	24	22
	Almost never	4	6
Felt good about yourself	A lot	57%	53%
	Sometimes	38	44
	Almost never	5	4
Felt sad	A lot	5%	4%
	Sometimes	46	38
	Almost never	48	57
Felt lonely	A lot	7%*	3%
	Sometimes	24	27
	Almost never	68	69

Note: Small proportions of respondents (1% or less) who answered "don't know" or who did not answer are not shown in the table above.

* Significantly higher than counterparts (at .95 level)

Feelings and Self Perceptions

Children's feelings about themselves and their perceptions of how others relate to them indicate that caregiving has some negative impacts. In other ways, caregivers come out ahead, with feelings or perceptions that are more positive than those of non-caregivers.

One way in which caregiving negatively affects caregivers is that they have marginally less time for themselves than non-caregivers; 38% say they have time for themselves *a lot*, compared to 47% of non-caregivers who say this is the case [see Table 9]. In addition, caregivers are more likely to feel frequently that it is no use letting their feelings show (caregivers 18% vs. 11% non-caregivers). This finding is driven exclusively, however, by differences between male caregivers (26%) and non-caregivers (11%).

One of the positive effects of caregiving is that caregivers are more likely to feel appreciated for the help they give at home or to other people they know; 64% report feeling this way *a lot*, compared to 53% of non-caregivers. Interestingly, caregivers are *less* likely to feel that people often expect too much from them (12% vs. 19%) and slightly less likely to frequently feel angry about all of the things they have to do (8% vs. 13%).

Caregivers' and non-caregivers' perceptions of productivity are similar, with 41% and 39%, respectively, feeling as if they have productive days *a lot*. Equal proportions of both groups also often feel that grown-ups will listen to their problems (55% each). They are also about equally likely to feel often that there is no one they can depend on but themselves (caregivers 7% vs. non-caregivers 11%).

- Several of the significant differences between caregivers and non-caregivers noted above are not apparent among the oldest children (ages 16 to 18). Caregivers' less frequent perception of having time for themselves is not present among 16- to 18-year-olds, nor is this group less likely than non-caregivers of this age to feel angry about all they have to do. In addition, it is only among 12- to 15-year-olds that caregivers are less likely than non-caregivers to feel people often expect too much from them.
- Although the finding that caregivers feel more appreciated for their help is apparent in all age groups, the gap between caregivers and non-caregivers in feeling appreciated *a lot* it is much greater among 8- to 11-year-olds (79% vs. 59%).
- Negative feelings are more evident among caregivers who help with ADLs. For example, 49% of child caregivers who help with ADLs feel, at least *sometimes*, they cannot depend on anyone else, compared to 31% of child caregivers who help only with non-ADL tasks. Further, the ADL caregivers are twice as likely to feel *a lot* that people expect too much from them (16% vs. 7%) and that it is no use letting their feelings show (23% vs. 12%).
- Caregivers in minority households are twice as likely as those in non-minority households to report they feel *a lot* that it is no use letting their feelings show (33% vs. 15%).
- Caregivers who co-reside with their care receiver are less likely than those who live separately to feel often that they had a productive day (36% vs. 50%).

Table 9
Feelings and Self-Perceptions

		<i>"How often do you feel..."</i>	
		<u>Caregivers</u> (n=213)	<u>Non-Caregivers</u> (n=250)
<u>Positive Feelings/Self-Perceptions</u>			
If you talk to grown-ups about a problem, they listen to you	A lot	55%	55%
	Sometimes	36	39
	Almost never	8	5
As if you had a productive day	A lot	41%	39%
	Sometimes	51	53
	Almost never	8	7
Appreciated for the help you give at home or to other people you know	A lot	64%*	53%
	Sometimes	29	41*
	Almost never	7	6
You have time for yourself	A lot	38%	47%**
	Sometimes	55	47
	Almost never	6	6
<u>Negative Feelings/Self-Perceptions</u>			
There's no one you can depend on but yourself	A lot	7%	11%
	Sometimes	34	33
	Almost never	58	56
Angry about all of the things you have to do	A lot	8%	13%**
	Sometimes	58	54
	Almost never	33	33
People expect too much from you	A lot	12%	19%*
	Sometimes	57	51
	Almost never	31	30
It is no use letting your feelings show	A lot	18%*	11%
	Sometimes	50	50
	Almost never	28	39*

Note: Small proportions of respondents (2% or less) who answered "don't know" or who did not answer are not shown in the table above.

* Significantly higher than counterparts (at .95 level)

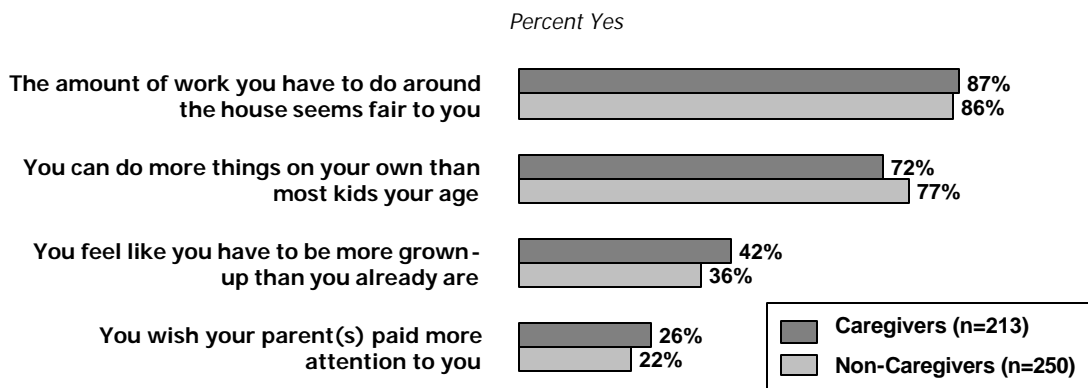
** Significantly higher than counterparts (at .90 level)

A large majority of caregivers report that the amount of work they have to do around the house seems fair to them (87%), and an equal proportion of non-caregivers say the same (86%) [see Figure 9]. Male caregivers are marginally more likely than male non-caregivers to perceive their share of housework as fair (92% vs. 85%), whereas no such difference is apparent for females (83% vs. 87%).

Interestingly, about three-quarters of both caregivers (72%) and non-caregivers (77%) feel they can do more things on their own than most kids their age. About four in ten caregivers feel like they have to be more grown-up than they already are (42%), and a similar proportion of non-caregivers feel this way (36%). The proportions wishing that their parents paid more attention to them are also similar for the two groups, with roughly one-quarter of each saying this is the case (caregivers 26% vs. non-caregivers 22%).

- Among the youngest children (8 to 11 years old), caregivers are more likely than non-caregivers to say the amount of work they have to do around the house is fair (92% vs. 79%). However, these same caregivers are less likely to say they can do more on their own than other kids (61% vs. 76%).

Figure 9
Additional Feelings and Self-Perceptions



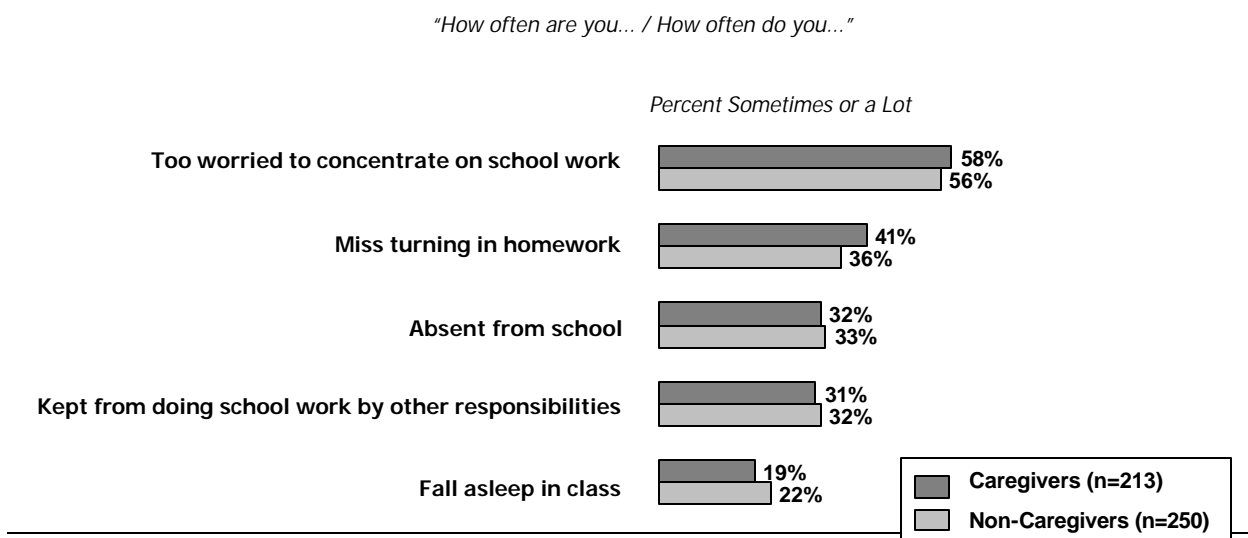
F. School Problems

Frequency of School Problems

Caregivers' experience of problems related to schoolwork mirrors non-caregivers' experience closely. At least *sometimes*, over half of both groups are too worried to concentrate on school (caregivers 58% vs. non-caregivers 56%), and roughly four in ten say they miss turning in homework *sometimes* or *a lot* (caregivers 41% vs. non-caregivers 36%) [see Figure 10]. About three in ten report that they are sometimes absent from school (32% vs. 33%) or that other responsibilities keep them from doing schoolwork (31% vs. 32%). One in five sometimes fall asleep in class (19% vs. 22%).

- Not submitting a homework assignment is more common among caregivers ages 8 to 15 (43% *sometimes* or *a lot*) than non-caregivers in this age group (33%).
- It is also more common for caregivers who live with their care receiver to encounter this problem more often than those who live separately (47% vs. 29% *sometimes* or *a lot*).
- Caregivers who help with ADLs are more likely than caregivers who only help with IADLs or other tasks to be absent from school, at least *sometimes* (38% vs. 24%).

Figure 10
School Problems

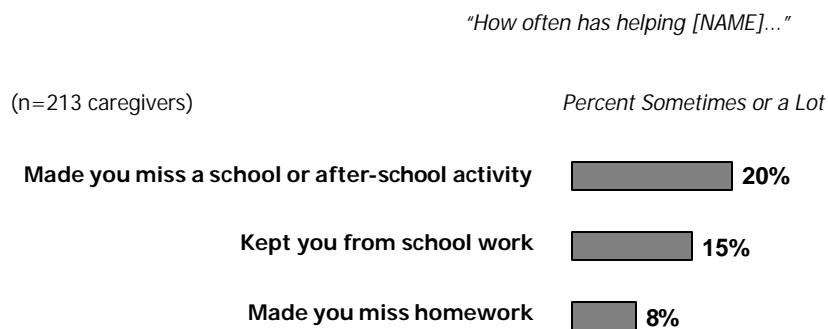


Impact of Caregiving on School

One in five caregivers say that caregiving has made them miss a school or after-school activity (20%), and smaller proportions say it has kept them from doing school work (15%), or made them miss homework (8%) [see Figure 11].

- Caregivers who help with ADLs are twice as likely as other caregivers to report missing a school or after-school activity *sometimes* or *a lot* (25% vs. 12%).
- Caregivers who live in the same household as their care receiver are three times as likely as other caregivers to miss turning in homework, at least *sometimes* (10% vs. 3%).

Figure 11
Impact of Caregiving on School



APPENDIX A: OMNIBUS QUESTIONNAIRE TO ESTIMATE PREVALENCE

ADD TO DEMO SECTION:

CG-A. (IF Z6-A>1: Did any of these [NUMBER FROM Z6-A] adults turn 18 on their last birthday, or are they all 19 or older?)
(IF Z6-A=1: Did you turn 18 on your last birthday, or are you 19 or older?)

- 1 Any adult 18 years old
- 2 All/Respondent is 19 or older
- D Don't know
- R Refused

(ASK CG-1 IF PRESENCE OF CHILDREN 8-17 YEARS OLD OR CG-A = CODE 1; OTHERWISE SKIP TO NEXT INSERT.)

CG-1. Is there anyone living in your household, including yourself, who has a chronic illness, or who is frail, elderly, disabled, or has a mental illness?

- 1 Yes
- 2 No
- D Don't know (SKIP TO NEXT INSERT)
- R Refused (SKIP TO NEXT INSERT)

CG-2. Are there any adults or children living in your household who provide unpaid help or care to (CG-1=1: that person or any other relative/CG-1=2: any relative)? The relative 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.

- 1 Yes
- 2 No (SKIP TO NEXT INSERT)
- D Don't know (SKIP TO NEXT INSERT)
- R Refused (SKIP TO NEXT INSERT)

CG-3. Are there any children or young adults aged 8 to 18, living in your household, who help provide such care or assistance?

- 1 Yes
- 2 No (SKIP TO NEXT INSERT)
- D Don't know (SKIP TO NEXT INSERT)
- R Refused (SKIP TO NEXT INSERT)

CG-4. What are the ages of those children or young adults who help provide care?

(ALLOW UP TO 5 MENTIONS. RANGE FOR ALL IS 8 TO 18)

First child/young adult _____
Second child/young adult _____
Third child/young adult _____
Fourth child/young adult _____
Fifth child/young adult _____

NN No other children/young adults
RR Refused

CG-5. I'd like to learn in what ways (IF ONLY 1 CHILD MENTIONED IN CG-4: the child or young adult helps/IF 2+ IN CG-4: those children or young adults help) the person who is frail, chronically sick, disabled, or mentally ill.

(Does the child or young adult/Do any of the children or young adults)...

1 Yes
2 No
D Don't know
R Refused

- a. Help the person with dressing or feeding?
- b. Help the person with bathing or using the bathroom?
- c. Help the person get in and out of beds or chairs?
- d. Help the person with housework, grocery shopping or meal preparation?
- e. Help the person with transportation or getting around the community?
- f. Help the person take medication?
(ROTATE g1 AND g2—DO NOT ASK BOTH)
- g1. Arrange outside services for the person or help manage his or her finances?
- g2. Manage the person's finances or help arrange outside services for him or her?

APPENDIX B: MAIL PANEL SCREENING QUESTIONNAIRE

1. Are there any children or young adults aged 8 to 18 living in your household who provide any of the following types of unpaid help or care to any person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled, or mentally ill? (**Note: The person to whom they provide care may or may not live in your household**) "X" all that apply

Specifically, does any child or young adult help...

Yes

- | | |
|---|------|
| a. With household chores or meal preparation | ___1 |
| b. With dressing or feeding | ___1 |
| c. In taking medicine or talking to doctors and nurses | ___1 |
| d. Keep him/her company/provide emotional support | ___1 |
| e. With shopping | ___1 |
| f. With paperwork, bills, or arranging outside services | ___1 |
| g. Move around the house/get around the community | ___1 |
| h. With bathing or using the bathroom | ___1 |

- e. How many children or young adults aged 8 to 18, living in your household, provide such help or care to a person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill?

Write in # → _____

3. Is there anyone living in your household, including yourself, who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled, or mentally ill?

Yes ___1

No ___2

APPENDIX C: INTERVIEW QUESTIONNAIRE

***Follow-Up Questionnaire for Child Caregivers and Non-Caregivers
FINAL***

RECORD SAMPLE:

- Children who provide care..... 1
- Children who do not provide care..... 2

RECORD INTRODUCTION:

- First introduction..... 1
- Callback of person who has
made appointment for child..... 2 **[GO TO CALLBACK INTRO]**

REGULAR INTRODUCTION

Hello, my name is **[INTERVIEWER'S FULL NAME]** and I am calling on behalf of Marie Brighton of the Synovate Consumer Opinion Panel. May I please speak to **[PANEL MEMBER NAME]**?

[WHEN SPEAKING TO THE APPROPRIATE PERSON]

This is **[INTERVIEWER'S FULL NAME]** calling from the Synovate Consumer Opinion Panel regarding your response to a recent survey we sent to members of our panel like you. Currently, we are conducting a confidential research study about how children and young adults, aged 8 to 18, spend their time.

CALLBACK INTRODUCTION

Hello, my name is **[INTERVIEWER'S FULL NAME]** and I am calling on behalf of Marie Brighton of the Synovate Consumer Opinion Panel. May I please speak to **[PANEL MEMBER NAME]**?

[WHEN SPEAKING TO THE APPROPRIATE PERSON]

Hello, this is **[INTERVIEWER'S FULL NAME]** calling from the Synovate Consumer Opinion Panel. We spoke to you recently about a study we are conducting about how children and young adults, aged 8 to 18, spend their time. You told us that now was a good time to talk to **[CHILD'S NAME]** for a few minutes. Is he/she available now?

- Yes..... 1 **[GO TO CHILD INTERVIEW BEFORE Q13]**
- No/DK 2 **[GO TO S12, SCHEDULE CALLBACK]**
- Refused 3 **[TERMINATE]**

Confirming Caregiver/Non-Caregiver Status

- S1. **[RECORD GENDER OF PANEL MEMBER]**
 Male..... 1
 Female..... 2

First, I'd like to confirm some information you reported in a recent mail survey.

- S2. Are there any children or young adults aged 8 to 18 living in your household who provide unpaid help or care to *any* person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill? [As needed: The person who receives help or care does not need to live with you.]

[IF INITIAL "YES" ASK: Just to confirm, there is someone 8-18 who helps give care to someone else. Is that correct?**] IF YES, CONTINUE.**

- Yes..... 1 **[IF FROM CG SAMPLE, SKIP TO S4.]**
 No..... 2 **[IF FROM CG SAMPLE, CONTINUE.**
IF FROM NON-CG SAMPLE, SKIP TO S4.]
 DK/Ref..... 3 **[TERMINATE]**

- S3. **[IF FROM NON-CG SAMPLE AND S2=1 OR IF FROM CG SAMPLE AND S2=2]** Just to be sure we do not miss any of the ways in which an 8 to 18 year old may be helping someone, I'm going to read a list. To save time, I will use the word "ill" generally to mean ongoing health problems, chronic illness, and mental illness.

Does anyone in your household aged 8 to 18 provide unpaid help **[RANDOMIZE A-H]** for *any* person who is ill, disabled, elderly, or frail?

	Yes	No	DK	Ref
a. With household chores or meal preparation	1	2	8	9
b. With dressing or feeding	1	2	8	9
c. In taking medicine or communicating with doctors and nurses	1	2	8	9
d. Keeping company or providing emotional support	1	2	8	9
e. With shopping	1	2	8	9
f. With paperwork, bills, or arranging outside services	1	2	8	9
g. With moving around the house or getting around the community	1	2	8	9
h. With bathing or using the bathroom	1	2	8	9

[IF NO/DK/Ref TO ALL IN A-H, TERMINATE]

- S4. **CLASSIFY RESPONDENT AS CAREGIVER OR NON-CAREGIVER:**

- Caregiver **[IF CG SAMPLE] OR**
[IF NON-CG SAMPLE AND "YES" TO AT LEAST ONE ITEM IN S3]..... 1
 Non-Caregiver **[IF NON-CG SAMPLE AND S2=2]..... 2**

Selecting Child to Interview

Caregivers

S5. How many children or young adults aged 8 to 18, living in your household, provide unpaid help or care to *any* person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill? **[AS NEEDED: Do not count any children ages 7 or younger, and do not count anyone age 19 or older.] [MINIMAL ALLOWANCE IS NOT CONSIDERED "PAID." TO BE CONSIDERED "PAID," IT HAS TO BE A REGULAR DAILY OR HOURLY PAYMENT SPECIFICALLY FOR THE CAREGIVING.]**

- _____ **[RECORD NUMBER]**
 None 98 **[TERMINATE]**
 Don't know / refused..... 99 **[TERMINATE]**

S6. **[IF S5=1]** How old is that child who provides care? **[IF DK, PROMPT: Can you tell me about how old the child is, within a year or two? ACCEPT AVERAGE OF RANGE, ROUNDING UP.]**
[IF S5>1→ RANDOMLY SELECT ONE OF THE CHILDREN.] How old is the [xth oldest] of those children who provides care?

Selected child's age [IF DK/REF, TERMINATE]	Age in years _____	DK/Ref 99
---	----------------------------------	---------------------

S7. Is that child male or female?

- Male..... 1
 Female..... 2
(VOL) Don't know **[TERMINATE]** 8
(VOL) Refused **[TERMINATE]** 9

All

S5a. How many TOTAL children or young adults aged 8 to 18 live in your household **[IF S4=1: including both [those / the one] we just counted and those who do not provide help or care]**?

- _____ **[RECORD NUMBER]**
 None 98 **[TERMINATE]**
 Don't know / refused..... 99 **[TERMINATE]**

Non-Caregivers

S6a. **[IF S5a=1]** How old is that child? **[IF DK, PROMPT: Can you tell me about how old the child is, within a year or two? ACCEPT AVERAGE OF RANGE, ROUNDING UP.]**
[IF S5a>1→ RANDOMLY SELECT ONE OF THE CHILDREN AT FIRST. HOWEVER, AS WE APPROACH THE END OF FIELDING, QUOTAS WILL NEED TO MATCH THE AGE/SEX DISTRIBUTION OF CAREGIVERS.] How old is the [xth oldest] of those children?

	Age in years	DK/Ref
Selected child's age [IF DK/REF, TERMINATE]	_____	99

S7a. Is that child male or female?

- Male..... 1
 Female..... 2
(VOL) Don't know **[TERMINATE]** 8
(VOL) Refused **[TERMINATE]** 9

All

This study has two steps. First, I would like to ask you a few questions about your child **[IF CG: and about the person your child helps]**. Then, with your permission, I would like to speak directly with your child.

VERBAL CONSENT

Before we proceed, I would like to tell you about the interview so you feel comfortable having me talk to your child. I will be asking him/her about the kinds of things s/he typically does, including his/her responsibilities and free time activities. We will also talk about **[IF CG: the kinds of things s/he does for the person s/he helps care for and]** how his/her responsibilities affect him/her. Please be assured that your responses and your child's will be kept strictly confidential. Individual results will not be released to anyone. Responses from many people will be grouped together so that no one person's answers can be identified. If you'd like, you may to listen to the interview.

This study is very important. It will help us better understand how children's responsibilities affect them. We hope it will lead to policies and programs that will help support children. This project has been approved by the Towson University Human Subjects Review Board. If you have any questions regarding the use of the information you or your child provide, please contact the Review Board Chairperson, Dr. Patricia Alt, at (410) 704-2236.

S8. Based on this information about the study, may I interview the **[AGE]**-year old **[boy/girl]** we have been discussing?

- Yes..... 1 **[GO TO S11]**
- No, do not want the child interviewed..... 2 **[IF S5=1 or S5a=1, TERMINATE]**
- Yes, but child is not available..... 3 **[GO TO S11]**

S9. **[IF S8=2 and IF S5>1 or S5a>1, RANDOMLY SELECT ANOTHER CHILD]**

Alternatively then, may I interview the **[xth oldest]** child?

- Yes..... 1 **[GO TO S10]**
- No, do not want the child interviewed..... 2 **[TERMINATE]**
- Yes, but child is not available..... 3 **[GO TO S10]**

S10. **[ASK ONLY IF S9 = 1]** Is that child male or female?

- Male..... 1
- Female..... 2
- (VOL) Don't know [TERMINATE]** 8
- (VOL) Refused [TERMINATE]** 9

S11. What is his/her first name?

(VOL) Refused.....99

[IF REFUSED IN S12, USE "The child we are going to interview" AS "CHILD'S NAME".]

S12. **[IF S8=3 or S9=3]**

I would like to schedule a time to talk to him/her when you would also be at home. When would be the best day and time?

Day: _____ Date: _____ Time: _____

(VOL) Refused.....99 **[TERMINATE]**

[IF INTERVIEW SCHEDULED:] Thank you. We'll call back at this time to speak with **[CHILD'S NAME]**. While we have you on the phone, I have just a few more questions for you. **[SKIP TO Q1]**

[IF BOTH CHILD AND PANEL MEMBER AVAILABLE NOW] Thank you. Before we get him/her on the phone, I have just a few more questions for you.

Demographics and Information About Child and Care Receiver

1. How many total children ages 7 or younger live in your household?

_____ **[RECORD NUMBER]**

(VOL) Don't know / refused.....99

2. Do you have a spouse or partner who lives in your household?

Yes..... 1

No..... 2

(VOL) Don't know 8

(VOL) Refused 9

Now I am going to read some statements that describe behavior problems that many children have. Please tell me whether each statement has been OFTEN true, SOMETIMES true, or NOT true of **[CHILD's NAME]** during the past three months.

3. The first/next statement is **[ROTATE]**. In the past three months, has that been OFTEN true, SOMETIMES true, or NOT true of **[CHILD's NAME]**?

Anxious/Depressed and Antisocial Subscales of Nicholas Zill's Behavior Problems Index

		Often true	Some-times true	Not True	(VOL) DK	(VOL) Ref
a.	Has sudden changes in mood or feelings	3	2	1	8	9
b.	Feels or complains that no one loves him/her	3	2	1	8	9
c.	Is too fearful or anxious	3	2	1	8	9
d.	Feels worthless or inferior	3	2	1	8	9
e.	Is unhappy, sad, or depressed	3	2	1	8	9
f.	[IF AGE= 12+] Worries too much	3	2	1	8	9
g.	Cheats or tells lies	3	2	1	8	9
h.	Bullies, or is cruel or mean to others	3	2	1	8	9
i.	Is disobedient at school	3	2	1	8	9
j.	Does not seem to feel sorry after he/she misbehaves	3	2	1	8	9
k.	Has trouble getting along with teachers	3	2	1	8	9
l.	[IF AGE < 12] Breaks things on purpose, deliberately destroys his/her own or others' things	3	2	1	8	9
m.	[IF AGE= 12+] Hangs out with kids who get into trouble	3	2	1	8	9

Caregivers

4. Now I'd like to ask a few questions about the person to whom your child gives help or care. What is that person's relationship to **[CHILD'S NAME]**?

[IF MORE THAN ONE PERSON RECEIVING CARE: I'd like to focus on the one person to whom your child gives the most help or care. This is the person we will be talking about for the rest of the interview. What is that person's relationship to **[CHILD'S NAME]**?

[AS NEEDED: We're looking for whether the person is a relative or not, and if so, what type of relative.]

[DO NOT READ.]

Mother / Stepmother	1
Father / Stepfather.....	2
Grandmother.....	3
Grandfather.....	4
Aunt or great-aunt.....	5
Uncle or great-uncle.....	6
Sister or stepsister.....	7
Brother or step-brother.....	8
Other relative [specify].....	9
Non-relative / friend	10
(VOL) Don't know	11
(VOL) Refused.....	12

5. **[IF Q4=9 OR 10]** Is that person male or female?

Male.....	1
Female.....	2
(VOL) Don't know	8
(VOL) Refused	9

6. What is that person's age? **[IF NOT SURE:** Can you estimate?]

(VOL) Don't know.....	98
(VOL) Refused	99

7. What does **[CHILD'S NAME]** call the person he/she cares for?

[IF RESPONDENT DOES NOT WANT TO GIVE NAME: When I ask **[CHILD'S NAME]** how s/he helps the person who receives care, I need to somehow refer to that person so that the questions are clear.]

[USE THIS AS "CR NAME" THROUGHOUT SURVEY]

(VOL) Refused.....	99
---------------------------	----

8. What are the main health problems or conditions for which the person needs care? **[IF AGE CITED: Some older people do not need any help. What is the condition that causes him/her to need care?]**
[DO NOT READ] [AS NEEDED: Does the person have a particular illness or is it some other condition?]

[IF NO PARTICULAR CONDITION, BUT CAN'T DO THE THINGS THEY USED TO DO, LIKE REDUCED STRENGTH, COORDINATION, MOBILITY, MARK "FUNCTIONAL DECLINE"]

- | | |
|---|--|
| <input type="checkbox"/> 1 Alzheimer's / dementia | <input type="checkbox"/> 20 Functional decline |
| <input type="checkbox"/> 2 Amputation | <input type="checkbox"/> 21 Head injury |
| <input type="checkbox"/> 3 Arthritis | <input type="checkbox"/> 22 Heart / lung / kidney disease |
| <input type="checkbox"/> 4 Autism | <input type="checkbox"/> 23 High blood pressure |
| <input type="checkbox"/> 5 Birth defects | <input type="checkbox"/> 24 HIV/AIDS |
| <input type="checkbox"/> 6 Blindness / vision impairment | <input type="checkbox"/> 25 Incontinence |
| <input type="checkbox"/> 7 Bone / joint fractures or repairs | <input type="checkbox"/> 26 Memory problems |
| <input type="checkbox"/> 8 Brain injury / head injury | <input type="checkbox"/> 27 Mental illness |
| <input type="checkbox"/> 9 Cancer | <input type="checkbox"/> 28 Mental retardation, Downs Syndrome |
| <input type="checkbox"/> 10 Catheter | <input type="checkbox"/> 29 Multiple Sclerosis (MS) |
| <input type="checkbox"/> 11 Cerebral Palsy (CP) | <input type="checkbox"/> 30 Ostomy |
| <input type="checkbox"/> 12 Circulation problems/vascular disease | <input type="checkbox"/> 31 Paralyzed / spine injury |
| <input type="checkbox"/> 13 Crohn's Disease | <input type="checkbox"/> 32 Parkinson's Disease |
| <input type="checkbox"/> 14 Cystic Fibrosis | <input type="checkbox"/> 33 Stroke/TIA |
| <input type="checkbox"/> 15 Deafness / hearing impairment | <input type="checkbox"/> 34 Wound(s) |
| <input type="checkbox"/> 16 Depression | <input type="checkbox"/> 35 Other: _____ |
| <input type="checkbox"/> 17 Diabetes | <input type="checkbox"/> 98 (VOL) Don't know |
| <input type="checkbox"/> 18 Epilepsy / seizures | <input type="checkbox"/> 99 (VOL) Refused |
| <input type="checkbox"/> 19 Feeding tube | |

9. **[IF Q8 DOES NOT EQUAL 1]** Does the person have Alzheimer's, dementia, or mental confusion?

- Yes..... 1
 No..... 2
(VOL) Don't know 8
(VOL) Refused 9

10. Which of the following best describes the person's ability to get around? **[READ 1-4]**

[ONLY IF RESPONDENT MENTIONS CANES OR WALKERS: Can the person walk without help from another person or does he/she need help from another person?]

- They can walk WITHOUT help from another person..... 1
 They can walk WITH help from a person..... 2
 They cannot walk, but can use a wheelchair, or 3
 They are bedridden..... 4
(VOL) Don't know 8
(VOL) Refused 9

11. Does the person who receives help live in your household?

- Yes..... 1
 No..... 2
(VOL) Don't know 8
(VOL) Refused 9

All

Now that we have a little background information, I would like to speak to **[CHILD'S NAME]** for a few minutes about how s/he spends his/her time. You are, of course, welcome to stay on the phone while I speak with him/her. However, if you listen, we ask that you remain completely silent since any noise or comment you make may influence his/her responses. If you are uncomfortable with him/her answering a particular question, you may tell me to skip over it. However, we cannot stress enough how important it is that **[CHILD'S NAME]** answer the questions by him/herself. Could you bring **[CHILD'S NAME]** to the telephone and please encourage him/her to be as honest as possible.

[ANYTIME DURING INTERVIEW IF PARENT SPEAKS: Excuse me, Ma'am/sir. It is very important that **[CHILD'S NAME]** hear only the questions as I pose them, and nothing else. I cannot use his/her answers if you have said anything.]

Child's Interview

Hi **[CHILD'S NAME (OR SKIP NAME IF REFUSED TO GIVE IT IN S12)]**, my name is **[INTERVIEWER'S FIRST NAME]** and I want to ask you some questions about how you spend your time. If you are uncomfortable with any questions, let me know and we will skip it, ok?

12. Is it OK if we start now?

Yes.....1

No/DK/Ref.....2

[ASK FOR PARENT.]

[IF Q12 = 2, ONCE SPEAKING TO PARENT:]

[IF S5=1 OR S5a=1] Your child said he/she did not want to begin the interview. Thanks for your time. **[TERMINATE.]**

[IF S5>1 or S5a>1] **[CHILD'S NAME]** did not want to begin the interview. **[GO TO S9.]**

[ANYTIME DURING INTERVIEW IF CHILD SEEMS DISTRESSED: You seem to be upset. Are you? **IF NO, CONTINUE WITH INTERVIEW. IF YES, READ THE FOLLOWING:** There is a place where kids can call to talk about problems and feelings, and where they can get some help. Let me give you the phone number. Do you have something to write with? The phone number is 1-800-334-4123. Someone is there day and night. You would be calling a place called KidsPeace. Did you get the number down? Now, would you to continue with our questions or would you like to stop? **IF STOP, SKIP TO TERMINATION TEXT.]**

Time Spent on Activities

13. I'd like to ask you about how much time you spend doing certain activities.

In a normal week, how much time do you spend **[ROTATE]**? A lot, a little, or not at all?

		A lot	A little	Not at all	(VOL) DK	(VOL) Ref
a.	[CG ONLY] Helping take care of [CR NAME] ?	3	2	1	8	9
b.	Doing laundry	3	2	1	8	9
c.	Shopping for groceries	3	2	1	8	9
d.	Making dinner	3	2	1	8	9
e.	Washing dishes	3	2	1	8	9
f.	Sweeping, vacuuming, or dusting	3	2	1	8	9
g.	Doing homework	3	2	1	8	9
h.	In organized after-school or weekend activities—such as sports teams, clubs, scouts, or lessons for things like music, art, or dance	3	2	1	8	9
i.	[IF AGE <12] Playing with friends [IF AGE =12+] Hanging out with your friends	3	2	1	8	9
j.	Watching television [PLAYING VIDEO OR COMPUTER GAMES DO NOT COUNT AS WATCHING TV.]	3	2	1	8	9
k.	By yourself doing things you like, not counting watching TV	3	2	1	8	9
l.	[IF AGE =12+] Working at a job	3	2	1	8	9
m.	Taking care of brothers or sisters [IF CG AND Q4=7 OR 8 INSERT "other than [CR NAME]"	3	2	1	8	9

Self-Perception, Mood, Well-Being

14. In the past week, how often have you **[ROTATE]**? A lot, sometimes, or almost never?

		A lot	Some - times	Almos t Never	(VOL) DK	(VOL) Ref
a.	Had fun?	3	2	1	8	9
b.	Felt sad?	3	2	1	8	9
c.	Felt lonely?	3	2	1	8	9
d.	Felt good about yourself?	3	2	1	8	9

15. How much responsibility do you think you have overall? A lot, some, or almost none?

- A lot 3
- Some..... 2
- Almost none..... 1
- (VOL)** Don't know 8
- (VOL)** Refused 9

16. How often do you have to skip a fun activity because you have more important responsibilities? A lot, sometimes, or almost never?

[IF CHILD DOES NOT UNDERSTAND "RESPONSIBILITIES": How often do you have to skip a fun activity because you have more important things you have to do? A lot, sometimes, or almost never?]

- A lot 3
 Sometimes 2
 Almost never 1
(VOL) Don't know 8
(VOL) Refused 9

17. **[ROTATE]** A lot, sometimes, or almost never?

		A lot	Some-times	Almost Never	(VOL) DK	(VOL) Ref
a.	How often do you have time for yourself?	3	2	1	8	9
b.	How often do you feel as if you had a productive day? [IF CHILD DOES NOT UNDERSTAND "PRODUCTIVE": How often do you feel as if you got a lot done in a day?]	3	2	1	8	9
c.	If you talk to grown-ups about a problem, how often do you feel like they listen to you?	3	2	1	8	9
d.	How often do you feel like there's no one you can depend on but yourself?	3	2	1	8	9
e.	How often do you feel appreciated for the help you give at home or to other people you know?	3	2	1	8	9
f.	How often do you feel it is no use letting your feelings show?	3	2	1	8	9
g.	How often do you feel angry about all the things you have to do?	3	2	1	8	9
h.	How often do you feel like people expect too much from you?	3	2	1	8	9

18. Yes or no, **[ROTATE]**

		Yes	No	(VOL) DK	(VOL) Ref
a.	Can you do more things on your own than most kids your age?	1	2	8	9
b.	Does the amount of work you have to do around the house seem fair to you?	1	2	8	9
c.	Do you wish your parent(s) paid more attention to you?	1	2	8	9
d.	Do you feel like you have to be more grown-up than you really are?	1	2	8	9

Impact on Schoolwork

19. How often **[ROTATE]**? A lot, sometimes, or almost never?

		A lot	Some - times	Almos t Never	(VOL) DK	(VOL) Ref
a.	Are you absent from school?	3	2	1	8	9
b.	Do you miss turning in a homework assignment?	3	2	1	8	9
c.	Do your other responsibilities keep you from doing schoolwork? [IF CHILD DOES NOT UNDERSTAND "RESPONSIBILITIES": How often do other things you have to do keep you from doing schoolwork?]	3	2	1	8	9
d.	Are you too worried about something to concentrate on your schoolwork?	3	2	1	8	9
e.	Do you fall asleep during class time?	3	2	1	8	9

20. **[IF CG]** How often... **[ROTATE]**? A lot, sometimes, or almost never?

		A lot	Some - times	Almos t Never	(VOL) DK	(VOL) Ref
a.	Has helping [CR NAME] kept you from doing schoolwork?	3	2	1	8	9
b.	Has helping [CR NAME] made you miss turning in a homework assignment?	3	2	1	8	9
c.	Has helping [CR NAME] made you miss a school or after-school activity?	3	2	1	8	9

Nature of Caregiving

Caregivers

I understand that you help or care for **[CR NAME]**. I want to find out what you do for him/her.

21. Yes or no, do you help **[ROTATE]**?

[ASK Q22 IMMEDIATELY AFTER EACH "YES" IN Q21]

22. Does anyone else help with that too?

	Q21				Q22			
	Yes	No	DK	Re f	Yes	No	DK	Re f
a. [CR NAME] with household chores	1	2	8	9	1	2	8	9
b. Prepare meals for [CR NAME]	1	2	8	9	1	2	8	9
c. [CR NAME] get dressed	1	2	8	9	1	2	8	9
d. Feed [CR NAME]	1	2	8	9	1	2	8	9
e. [CR NAME] take medicine or pills or shots	1	2	8	9	1	2	8	9
f. [CR NAME] to talk with doctors or nurses	1	2	8	9	1	2	8	9
g. Keep [CR NAME] company	1	2	8	9	1	2	8	9
i. [CR NAME] with grocery shopping	1	2	8	9	1	2	8	9
j. [IF AGE 12+] [CR NAME] with paperwork or paying bills	1	2	8	9	1	2	8	9
k. [IF AGE 12+] Call or arrange for someone else to come in to help [CR NAME]	1	2	8	9	1	2	8	9
l. [CR NAME] get in and out of beds or chairs	1	2	8	9	1	2	8	9
m. [CR NAME] get around the neighborhood or city	1	2	8	9	1	2	8	9
n. [CR NAME] bathe or shower	1	2	8	9	1	2	8	9
o. [CR NAME] use the bathroom or diapers	1	2	8	9	1	2	8	9

23. How often does **[CR NAME]** confide in you? That means talking to you about things that he / she doesn't talk to anyone else about. A lot, sometimes, or almost never?

A lot 3

Sometimes 2

Almost never 1

(VOL) Don't know 8

(VOL) Refused 9

I want to thank you very much for talking to me today. You really helped me by taking the time to answer all of these questions. We hope that what we learn from you and other young people will be used to help children and young adults.

24. **[FOR INTERVIEWER ONLY]**

Did you give the child the toll free number for KidsPeace?

Yes..... 1

No..... 2 **[SKIP TO Q25]**

[IF Q24 = 1] May I please speak to your mom or dad?

[WHEN SPEAKING TO PARENT] Thanks for letting us to talk with **[CHILD'S NAME]**. I wanted to let you know that at one point in our conversation, he/she seemed upset, so I gave him/her a toll free phone number to call if he/she wants to talk to someone. The number is for a non-profit organization called KidsPeace that helps kids deal with their problems and feelings. I just wanted to let you know that this is an available resource and that I gave **[CHILD'S NAME]** the number. Do you also want the number? **[IF YES]** The phone number is 1-800-334-4123.

Thanks again for your time.

Interviewer's Assessment

25. How much of the time...
Did the child appear to understand the questions?

None of the time	A little of the time	About half the time	Most of the time	All of the time
1	2	3	4	5

(VOL) Don't know 8
(VOL) Refused 9

26. How much of the time...
Did the child appear to answer the questions randomly?

None of the time	A little of the time	About half the time	Most of the time	All of the time
1	2	3	4	5

(VOL) Don't know 8
(VOL) Refused 9

27. How much of the time...
Did the child appear to think about each response before answering?

None of the time	A little of the time	About half the time	Most of the time	All of the time
1	2	3	4	5

(VOL) Don't know 8
(VOL) Refused 9

28. How much of the time...
Was the parent listening on the phone when the child was interviewed?

None of the time	A little of the time	About half the time	Most of the time	All of the time
1	2	3	4	5

(VOL) Don't know 8
(VOL) Refused 9

Appendix D: Selected Bibliography

Africa

Bauman, L.J., Foster, G., & Silver, E.J. (July 2004). Children as caregivers to their ill mothers with HIV/AIDS. Poster presented at the 15th International AIDS Conference, Bangkok, Thailand.

Robson, E. (January 9, 2001). Interviews worth the Tears? Exploring Dilemmas of Research with Young Carers in Zimbabwe. *Ethics, Place and Environment*, 4(2):135-142.

Australia

Barnett, B., & Parker, G. (1998). The Parentified Child: Early Competence or Childhood Deprivation? *Child Psychology & Psychiatry Review*; 3(4):146-155.

Hughes, J., Sengstock, J., Malak, A., & Henderson, S. (October 2002). Young Carer Project Power Point Presentation for the Third International Conference on Family Care, Washington, DC.

Carers Australia (July 2002). Young Carers Research Project Final Report. Deakin, Australia: Author.

United Kingdom

Aldridge, J., & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy*, 21:303-320.

Aldridge, J. & Becker, S. (2003). *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*. Bristol, England: The Policy Press.

Becker, S., Aldridge, J., & Dearden, C. (1998). *Young Carers and Their Families*. Oxford, England: Blackwell Science.

Becker, S., & Dearden, C. (2004). *Young Carers in the UK: The 2004 Report*. London: Carers UK.

Baker, G. (undated). *Unseen and Unheard: The Invisible Young Carer*. London, England: Carers Lewisham and The Princess Royal Trust for Carers.

Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M., & Tisdall, K. (2002). Does the Covert Nature of Caring Prohibit the Development of Effective Services for Young Carers? *British Journal of Guidance & Counseling*; 30(3):219-246.

Dearden, C., & Becker, S. (2000). *Growing Up Caring: Vulnerability and Transition to Adulthood*. York, England: Youth Work Press for the Joseph Rowntree Foundation.

Earley, L., & Cushway, D. (April 2002). The Parentified Child. *Clinical Child Psychology and Psychiatry*; 7(2):163-178.

Frank, J. (2002). *Making It Work: Good Practice with Young Carers and their Families*. London: The Children's Society.

Keith, L., & Morris, J. (1995). Easy Targets: A Disability Rights Perspective on the "Children as Carers" Debate. *Critical Social Policy*, 44/45: 36-57.

Newman, T. (2002). "Young Carers" and Disabled Parents: Time for a Change of Direction. *Disability & Society*, 17(6):613-625.

Olsen, R. (1996). Challenging the Facts and Politics of Research into Children and Caring. *Disability & Society*, 11(1):41-54.

Olsen, R., & Holzhausen, E. (1999). Focus on Home. *The Journal of Young Carers Work*, 1: 4-7.

Olsen, R., & Parker, G. (1997). A Response to Aldridge and Becker—"Disability rights and the Denial of Young Carers: The Dangers of Zero-Sum Arguments." *Critical Social Policy*, 17:125-133.

Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S., & Webb, A. (2003). "Your Friends Don't Understand": Invisibility and Unmet Need in the Lives of "Young Carers." *Child and Family Social Work*, 8:35-46.

Wates, M. (2002). *Supporting Disabled Adults in the Parenting Role*. York, England: YPS.

United States

Anderson, L.P. (1999). Parentification in the Context of the African American Family. In Chase, N.D. (Ed.), *Burdened Children Theory, Research, and Treatment of Parentification* (pp. 154-170). Thousand Oaks, London & New Delhi: Sage.

Bauman, L., & Draimin, B. (2003). Children as Caregivers to their Ill Parents with AIDS: Final Report. New York: Ittleson Foundation.

Beach, D. (1997). Family Caregiving: The Positive Impact on Adolescent Relationships. *The Gerontologist*, 37(2): 233-238

Bovino, A. (December 30, 2002). Misfortune Stalks A Mother and Child. *The New York Times*.

Chase, N.D. (1999). Parentification: An Overview of Theory, Research, and Societal Issues. In Chase, N.D. (Ed.), *Burdened Children Theory, Research, and Treatment of Parentification* (pp. 3-33). London & New Delhi: Sage, pp. 3-33.

Dellmann-Jenkins, M., Blankemeyer, M., & Pinkard, O. (2000). Young Adult Children and Grandchildren in Primary Caregiver Roles to Older Relatives and Their Service Needs. *Family Relations*, 49:177-186.

Dellmann-Jenkins, M., Blankemeyer, M., & Pinkard, O. (2001). Incorporating the Elder Caregiving Role into the Developmental Tasks of young Adulthood. *International Journal of Aging and Human Development*, 52(1):1-18.

Draimin B., & Shire, A. (2002). A Study of Young Caregivers: Observations/Emerging Themes. New York: The Family Center.

Gates, M. & Lackey, N. (1998). Youngsters Caring for Adults with Cancer. *IMAGE Journal of Nursing Scholarship*, 30(1):11-15.

Jurkovic, D.J. (1997). Wounded Healer: From Parentified Child to Helping Professionals. In *Lost Childhood: The Plight of the Parentified Child* (pp. 169-198). New York: Brunner/Mazel.

Lackey, N.R., & Gates, M.F. (2001). Adults' Recollections of their Experiences as Young Caregivers of Family Members with Chronic Physical Illnesses. *Journal of Advanced Nursing*, 34(3):320-328.

Lamorey, S. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Chase, N.D. (Ed.), *Burdened Children Theory, Research, and Treatment of Parentification* (pp. 75-91). Thousand Oaks, London & New Delhi: Sage.

Nanuet Teen's Support Book. (Winter 2003). *MS Connection*; National MS Society.

Orel, N.A., & Dupuy, P. (2002). Grandchildren as Auxiliary Caregivers for Grandparents with Cognitive and/or Physical Limitations: Coping Strategies and Ramifications. *Child Study Journal*, 32(4):193-213.

Pollack, E.G. (Fall 2002). The Childhood We Have Lost: When Siblings Were Caregivers, 1900-1970. *Journal of Social History*, 36(1): 31-61.

Robinson, B.E. (1999). Workaholic Children: One Method of Fulfilling the Parentification Role. In Chase, N.D. (Ed.), *Burdened Children Theory, Research, and Treatment of Parentification* (pp. 56-74). Thousand Oaks, London & New Delhi: Sage.

Rolland, J.S. (1999). Parental Illness and Disability: A Family Systems Framework. *Journal of Family Therapy*, 21:242-266.

Shifren, K. (October 13, 2002). Early Caregiving Experiences: Effects on Adult Development. Presentation at the Third International Conference on Family Care, Arlington VA.

Shifren, K., & Kachorek, LV. (2003). Does Early Caregiving Matter? The Effects on Young Caregivers' Adult Mental Health. *International Journal of Behavioral Development*, 27(4):338-346.

Siskowski, C.T. (2004). Middle School Responses to Family Health Questions: The Effects of Family Caregiving on the Education of Middle School Students with Family Health Issues. Ph.D. dissertation, Lynn University, Boca Raton, FL. A summary of the findings is available at www.boca-respite.org/children.doc.

Sessions, M.W., & Jurkovic, G.J. (1997). Appendix B: Parentification Questionnaire. In Jurkovic, D.J. (Ed.), *Lost Childhood The Plight of the Parentified Child* (pp. 219-222). New York: Brunner/Mazel.

Zill, N. (1990). Behavior Problems Index Based on Parent Report [memorandum]. Washington, DC: Child Trends.