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# **Caregivers of Children: A Focused Look at Those Caring for A Child with Special Needs Under the Age of 18**

National Alliance for Caregiving  
in collaboration with

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## A Focused Look at Caregivers of Children with Special Needs

This is the first of three companion reports to the full report of the Caregiving in the U.S., 2009 study. This companion report focuses on 173 people who are providing care to a child under the age of 18, and includes comparisons to 1,296 caregivers of adults when significantly different. The other companion reports provide detail on caregivers of younger adults (age 18 to 49) and caregivers of older adults (age 50+). All caregivers were interviewed by telephone between March 5 and June 17, 2009. To see the complete study results, or for more information about the questionnaire or the methodology, please reference the full report and Appendices A and B.

### A. Prevalence of Caregiving in Households

There are an estimated 16.8 million unpaid caregivers who provide care to a child with special needs under the age of 18 in the U.S. The caregiving is defined as being due to a medical, behavioral, or other condition or disability—whether the condition is ongoing or a serious short-term medical condition, an emotional or behavior problem, or a developmental problem. Examples of such conditions include attention deficit disorder, autism, mental or emotional illness, Down's syndrome, developmental delays, asthma, etc.

### B. Basics of the Caregiving Situation

Half of caregivers of children with special needs take care of one care recipient (51%). One-third (36%) care for two people, including any adults and children they might care for, and another 12% care for three or more people. Caregivers of children are less likely than caregivers of adults to be caring for just one person (51% vs. 68% respectively).

Half of caregivers of children are providing care to their own son or daughter (55%). Child care recipients are also commonly a grandchild (18%), another relative such as a niece or nephew (13%), a friend (8%), or some other non-relative (5%). The remaining 1% provide care to a younger sibling.

Most caregivers of children are female (72%) and on average, they are 40.6 years old. As might be expected, they are younger than caregivers of adults (49.2 years of age, on average). They care for a child that is 8.7 years old, on average. One in four caregivers of children (26%) are providing care to a child under the age of 5, 30% care for a 5- to 9-year-old, and 44% care for a child age 10 to 17.

Most child recipients are male (59%), whereas only 35% of adult recipients are male. Caregivers of children are significantly younger than those caring for an adult (on average, 49.2 years old), not surprising given that half of them are parents of their young care recipient.

Caregivers of children with special needs have, on average, been providing care for 4.2 years. Over four in ten feel they had *no* choice in taking on their caregiving responsibility (45%).

## C. Caregiving Activities and Burden of Care

### Help with Activities of Daily Living (ADLs)

Nearly half of caregivers of children with special needs (47%) help the child with at least one Activity of Daily Living (ADL). It is important to note that, in order to distinguish caregiving from typical parenting or child care, caregivers' help with each ADL was asked to be reported only if it was because the child was less able to do that particular task than other children of the same age without his/her condition. Further, ADLs performed for children under a certain age were not counted, since it would be expected that any very young child would need assistance. (See table below for threshold ages.) Performance of ADLs for these reasons is *less* common for caregivers of children than it is for caregivers caring for an adult (58% help with at least one ADL). The ADLs most commonly performed for children are grooming tasks: getting dressed (35%) and bathing or showering (28%).

**Figure 1: Performance of ADLs by Age of Recipient**

*Q22. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself...Do/did you help your [relation] with [ADL] because he/she is/was less able to do this task than children of the same age without his/her condition?*

	Recipient Age 0 to 17 (n=173) <sup>1</sup>	Recipient Age 18 or older (n=1,296)
Any ADL	47%	58%*
Get dressed [recipient age>3]	35%	32%
Bathe or shower [age>5]	28%	26%
Get in and out of beds and chairs [age>2]	23%	42%*
By feeding him or her [age>2]	20%	19%
Get to and from the toilet [age>3]	16%	25%*
By dealing with incontinence or diapers [age>3]	16%	19%

<sup>1</sup> The n size for each item varies. For ages >2, n=153; for ages >3, n=139; for ages >5, n=123.

## Help with Other Supportive Activities

Caregivers of children with special needs help their care recipient with 5.6 out of nine caregiving support activities as a result of the child's condition<sup>2</sup> (CSAs), on average. A large majority of caregivers of children help by monitoring the child's condition (85%), by ensuring that others know how to deal with him/her (84%), and by advocating on his/her behalf with schools, government agencies, or care providers (72%). Six in ten perform treatments or therapies for learning, emotional or behavioral issues (65%), give medicines or injections (64%), or deal with financial issues (63%). Four in ten are involved in giving physical or medical therapies (44%), preparing a special diet (40%), or arranging/supervising outside services (39%).

Among the two CSAs asked of both caregivers of children and caregivers of adults, those caring for a child are more likely to perform each: advocacy on behalf of the care recipient (72% vs. 52% caregivers of adults) and performing physical or medical therapies (44% vs. 22%).

## Hours of Care Provided

Based on the hours they spend helping with the ADLs and supportive activities above, caregivers of children with special needs have a more intensive caregiving experience than caregivers of adults. On average, caregivers of children spend 29.7 hours per week providing care, nearly 11 hours more per week than caregivers of adults 18 or older (18.9).<sup>3</sup> One in four provide care for at least 41 hours a week (24%).

**Figure 2: Hours of Care Provided**

*Q25. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you spend in an average week doing these things?*

	Recipient Age 0 to 17 (n=173)	Recipient Age 18 or older (n=1,296)
<i>Average Hours of Care</i>	29.7 <sup>4</sup>	18.9
Less than 1 hour	2%	3%
1 to 8 hours	29	48*
9 to 20 hours	24	23
21 to 40 hours	18	13
41 or more hours	24*	11

<sup>2</sup> There is an established list of Instrumental Activities of Daily Living (IADLs) that pertain to adult caregiving. However, caregivers of children were asked about several new IADL-like tasks (called CSAs), since it would be routine for parents, babysitters, and caregivers alike to help children with the standard IADLs.

<sup>3</sup> Any reports of constant care or caregiving in excess of 98 hours per week are capped at this level, equivalent to 14 hours per day.

<sup>4</sup> Throughout this report, an asterisk (\*) indicates a figure is statistically greater than the comparison figure.

## Burden of Care

Balancing the greater hours of care they provide against the fact they perform fewer ADLs, the net average "burden of care" for caregivers of children is still higher than it is for caregivers of adults.<sup>5</sup> In particular, they are less likely to be in a low burden situation (38% vs. 48% caregivers of adults). One in five (21%) caregivers of children are in medium-burden situations, and 39% are in high burden situations—not statistically different from the 31% of adult caregivers who are in such situations.

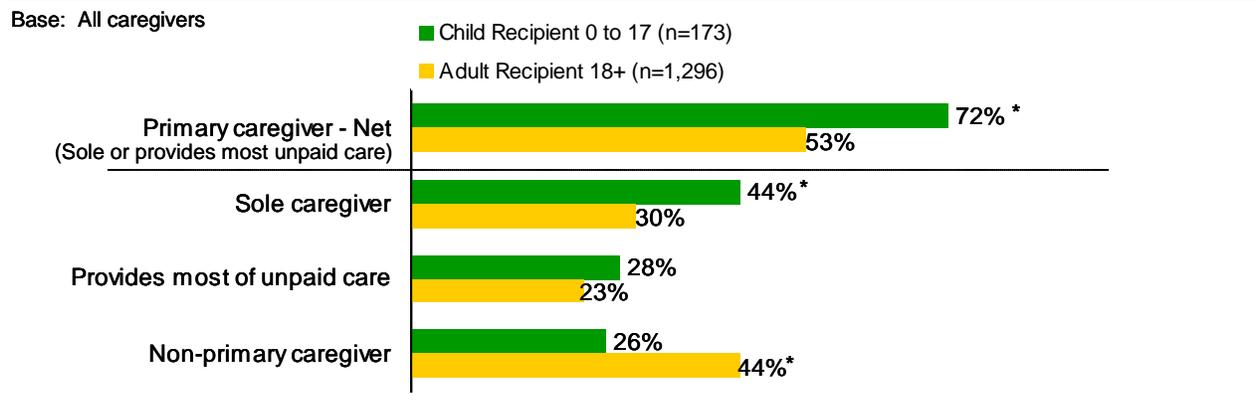
## D. Presence of Other Caregivers

Caregivers of children are more likely to be the sole unpaid caregivers than are caregivers of adults. While 54% of caregivers of children report someone else has also provided unpaid care to the child within the past 12 months, significantly more caregivers of adults report having this assistance (68%).

Seven in ten caregivers of children perceive themselves to be the primary caregiver (72%), including 44% who are sole caregivers and 28% who report that there are other unpaid caregivers but that they provide the most care to the child. Caregivers of children are more likely to be the primary unpaid caregiver than are caregivers of adults (53%).

**Figure 3: Primary Caregiver Status**

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?  
 Q29. Who would you consider to be the person who provides/provided most of the unpaid care for your [relation]—you yourself, or someone else?



Among caregivers caring for a child, 35% say their child care recipient had paid help from aides, housekeepers or others during the last 12 months. Most caregivers of children who use paid services (67%) maintain they are still the ones providing the most care. They are twice as likely as caregivers of adults (32%) to say so.

<sup>5</sup> "Burden of Care" is an index which is based on the number of hours of care provided by the caregiver, the number of Activities of Daily Living performed, and the number of Instrumental Activities of Daily Living (or Caregiving Support Activities for caregivers of children). Points are assigned for each of these, and ultimately, these points are consolidated into three burden categories: low, medium, and high. See Appendix B for the details of creating the index.

## E. Care Recipient Living Situation

Caregivers of children with special needs are more likely to live with their child care recipient (65%) than are caregivers of adults (23%), not surprising since half are a parent of the child they are caring for and 96% of those parents live with their child recipient. Virtually all of the rest of the care recipients (34%) live in a home setting. Eight in ten (84%) of the caregivers who do not live with their child recipient visit the child at least once a week.

Of the child care recipients who live neither with their caregiver nor in a facility, group setting, or foster care, most live with their parents (84%) and the rest live with other family members (16%). These child recipients who live apart from their caregivers are typically the caregiver's grandchild, niece/nephew, or a non-relative, although in a few cases, they are the caregiver's own child.

## F. Care Recipient's Condition

Six in ten caregivers of children with special needs report that their loved one needs care because of a learning disability or educational issue (61%), and/or an emotional or mental health problem (57%). Long-term physical conditions are a reason for care in half of the cases (52%). Caregivers of children are many times more likely than caregivers of adults to characterize their care recipient's condition as a learning/educational issue or mental retardation/developmental delay, and at least twice as likely to indicate there is an emotional/mental condition or a behavioral issue.

**Figure 4: Types of Care Recipient Conditions by Age of Recipient**

*Q17. Would you say that your [relation] needs/needed care because of any...?  
[MULTIPLE RESPONSES ALLOWED]*

	Recipient Age 0 to 17 (n=173)	Recipient Age 18 or older (n=1,296)
Learning disability or educational issue	61%*	8%
Emotional or mental health problems	57%*	28%
Long-term physical conditions	52%	71%*
Behavioral issues	45%*	13%
Mental retardation or developmental delay	41%*	5%
Short-term physical conditions	30%	36%

According to their caregivers, the top five main problems or illnesses for which child recipients need care are: attention deficit disorder, autism, mental/emotional illness, mental retardation, and asthma. Adult care recipients are significantly less likely to have each of these as their main problem or illness, with the exception of mental or emotional illness.

**Figure 5: Top Five Main Problems or Illnesses of Child Care Recipient by Age of Recipient**

Q18. What would you say is/was the main problem or illness your [relation] has/had, for which he/she needs/needed your care?

	Recipient Age 0 to 17 (n=173)	Recipient Age 18 or older (n=1,296)
Attention deficit disorder or ADHD	18%*	1%
Autism	11%*	<.5%
Mental/emotional illness, depression	10%	7%
Mental retardation, developmental delay	9%*	2%
Asthma, breathing	4%*	1%

Seven in ten of caregivers of children say their child care recipient is limited in his/her ability to do things that most children of the same age do (70%). The same percentage report the child takes prescription medications (70%), significantly fewer than the 93% reported by caregivers of adults. The majority of caregivers of children who take medicine (excluding those caring for a child under the age of eight) say the child care recipient needs help to take it properly (84%). In contrast, only 46% of adult care recipients need medication assistance.

About half of caregivers of children feel it is *very* or *somewhat* easy to coordinate the various health care professionals and service providers for their child care recipient (55%). Nevertheless, they are more likely than caregivers of adults to find care coordination at least somewhat difficult (40% vs. 23%).

## G. Strain and Stress of Caregiving

### Caregiver Health

While caregivers of children with special needs are younger than caregivers of adults, they give lower ratings to their health. Four out of ten caregivers of children consider their health to be *excellent* or *very good* (44%) compared to six in ten (59%) caregivers of adults, and 26% say their health is *fair* or *poor*, compared to 16% of those caring for adult care recipients. Caregivers of children are twice as likely as the general adult population to say they are in *fair/poor* health (26% vs. 13%).<sup>6</sup>

<sup>6</sup> Source: Provisional Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2008, dated August 2009.

One-quarter of caregivers of children feel caregiving has made their health worse (24%). Six in ten believe their health has *not* been affected by caregiving (63%), and 12% feel that taking care of their loved one has made their health better. The proportion reporting that their health worsened does not appear to be significantly different from the share of caregivers of adults who say this is the case (16%).

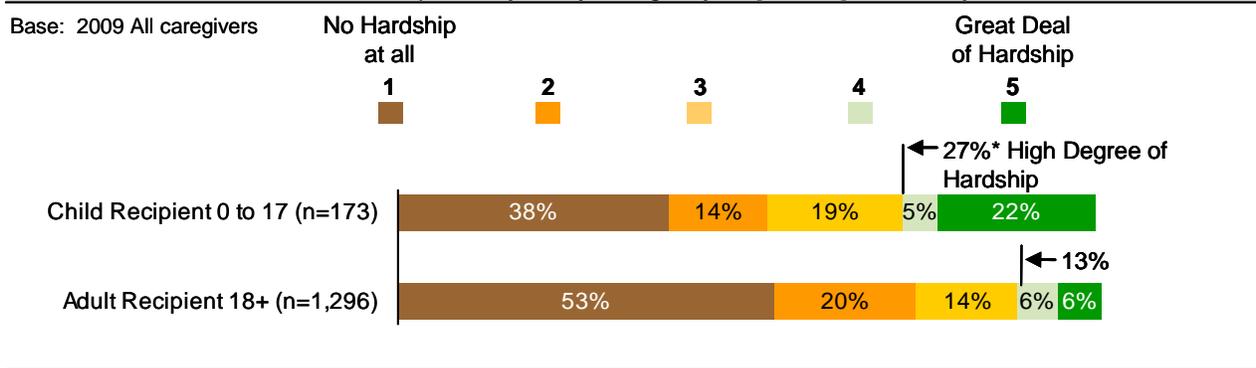
### Strain and Stress

Physical strain from caregiving is more common among caregivers of children with special needs (64%) than it is among those caring for adults (55%). However, only 17% face a high level of strain (4 to 5 on a 5-point scale). Emotional stress levels are similar for caregivers of children and adults. One-third of caregivers caring for a child consider their caregiving situation to be emotionally stressful (34% rating stress 4 to 5 on a 5-point scale), about the same proportion indicate little to no stress (37% rating 1 to 2). Another 28% rate their emotional stress level as moderate.

Majorities of caregivers of children with special needs report that caregiving has affected their social and financial well-being. Six out of ten caregivers of children (60%) say their caregiving limits the amount of time they spend with other family and friends. In addition, caregivers of children are more likely to feel at least some financial hardship as a result of caring for their loved one than their counterparts who care for an adult, and twice as likely to feel strong financial hardship. One in three of caregivers of children have sought financial assistance on behalf of the child (32%).

**Figure 6: Financial Hardship of Caregiving by Age of Recipient**

Q37. Please think of a scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship. How much of a financial hardship would you say caring for your [relation] is/was for you?



## H. Impact of Caregiving on Work

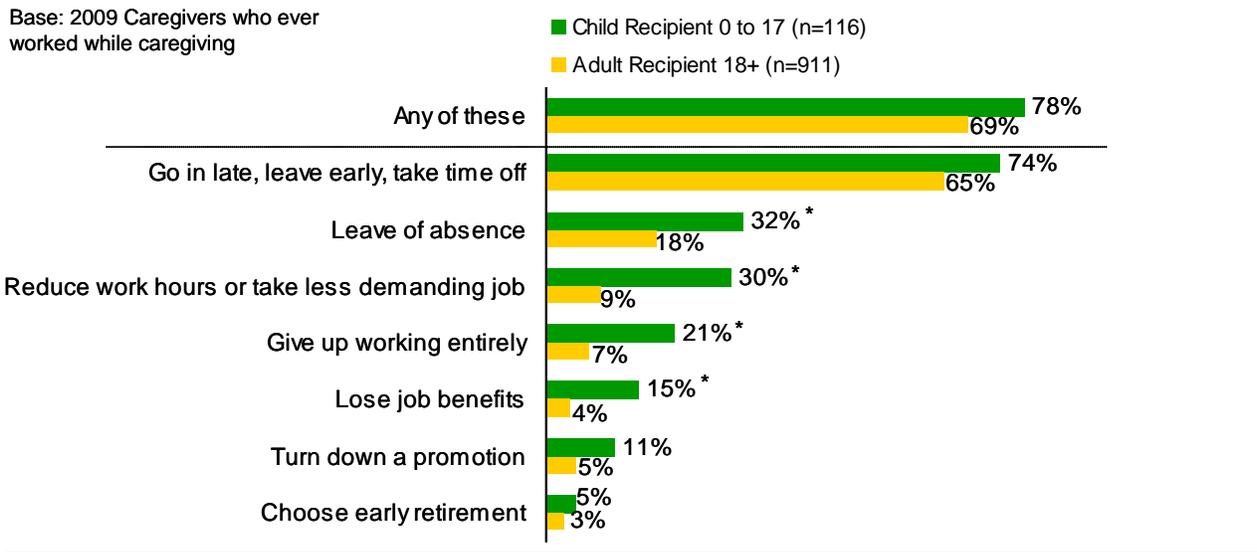
Seven in ten caregivers of children with special needs indicate they were employed at some time when they were caregiving (70%). Just over half are currently employed (53%), with 35% working full time and 18% working part time. By comparison, 64% of the adult civilian population is employed, including 71% of men and 58% of women.<sup>7</sup>

One in seven are homemakers (14%), and smaller shares are unemployed and looking for work (12%), disabled (8%), retired (7%), or students (4%). Caregivers of children are less likely than caregivers of adults to be working full time (35% vs. 48%) or retired (7% vs. 16%), and are more likely to be working part time (18% vs. 9%).

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

**Figure 7: Work Accommodations Due to Caregiving by Age of Recipient**

Q34. In your experience as both a worker and a caregiver, did you ever...?



<sup>7</sup> Source: Community Population Survey, 2008.

## I. Information Sources and Needs

### Sources of Information

When asked where they would turn for information related to caregiving, nearly four in ten caregivers of children with special needs would seek out a health or caregiving provider (38%)—especially a doctor (27%) or a nurse (12%). Another one in four volunteer that they would turn to the Internet (24%), while two in ten would rely on family, friends, and other caregivers (22%). Compared to caregivers of adults, caregivers of children are more likely to turn to a school for information (5% vs. 1% caregivers of adults) or a church/minister (6% vs. 2%).

### Internet Usage

When asked about their Internet usage in the past year to find caregiving information, 67% of caregivers of children report going online, surpassing the 51% of caregivers of adults who did. The fact that caregivers of children are nine years younger, on average, than caregivers of adults may partly explain this difference. Those who have looked on the Internet for caregiving information most commonly seek information about the child’s condition or treatment (81%) or information about services available for him/her (63%). Caregivers of children are more likely than caregivers of adults to search for information about how to do caregiving tasks or about support for themselves as caregivers; they are less likely to look for information on care facilities.

**Figure 8: Topics Searched Online by Age of Recipient**

*Q43. Did you look online for...?*

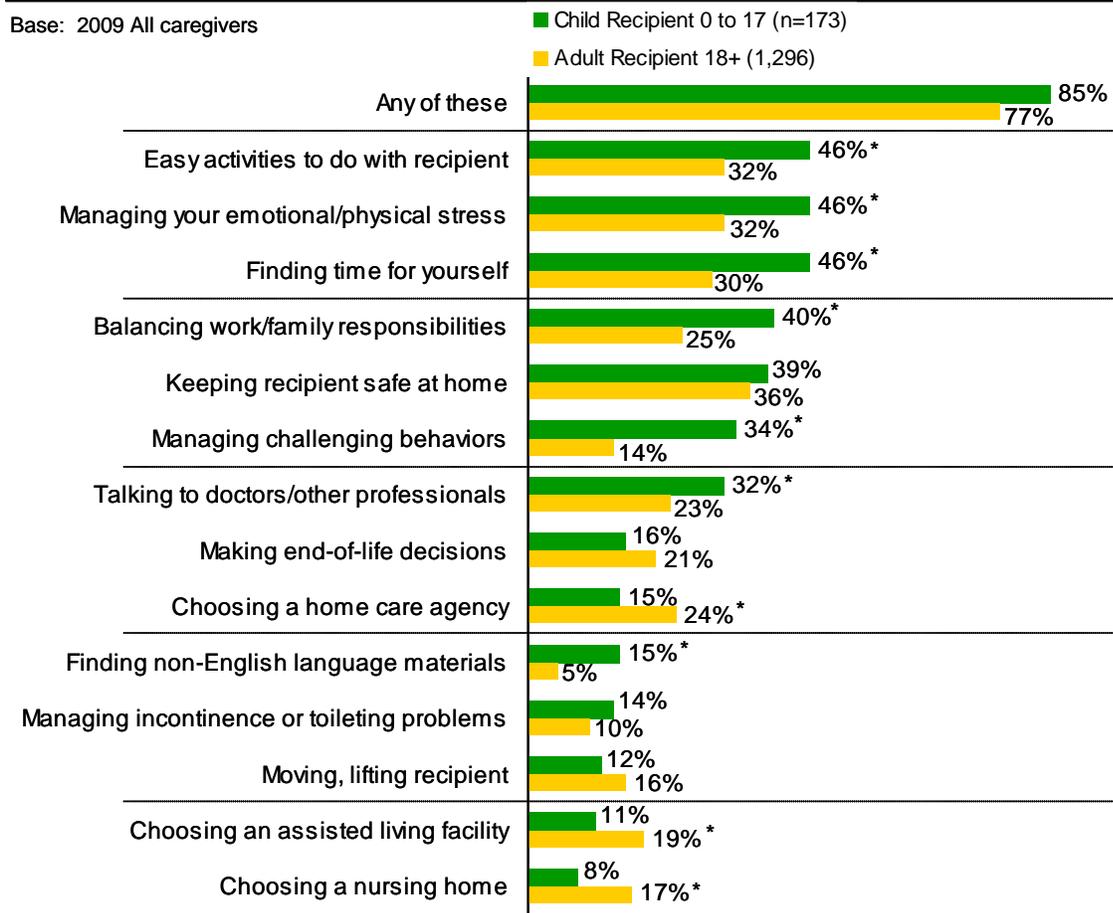
Base: Caregivers who searched online for information	Recipient Age 0 to 17 (n=109)	Recipient Age 18 or older (n=657)
Information about your [relation]’s condition or treatment	81%	77%
Information about services available for people like your [relation]	63%	56%
Information about how to do specific caregiving tasks	44%*	22%
Doctors or other health professionals	43%	34%
Support for you personally as a caregiver	27%*	10%
Information about care facilities	26%	36%*

## Information Needs

A large majority of caregivers of children with special needs feel they need more help or information about at least one topic related to caregiving (85%), more so than those caring for an adult (77%). Caregivers of children are more likely than caregivers of adults to want information related to their own well-being (stress management, family-work balance, time for self); communication (talking with doctors, non-English materials); and child recipient behavior (easy activities, managing challenging behaviors).

**Figure 9: Caregiving Information Needs by Age of Recipient**

Q48. As a caregiver, on which of the following topics do/did you feel you need/needed more help or information?



Consistent with their greater desire for help or information, caregivers of children are more likely to have obtained formal caregiver training (36% vs. 16% caregivers of adults.)

## J. Support for Caregivers

### Supportive Services and Practices

One in four caregivers of children with special needs have used an outside transportation service (24%). They are also more likely to have used a respite service or a sitter than caregivers of adults (19% vs. 11%).

About one-quarter of caregivers of children report having made home modifications to make things easier for their child care recipient (23%), significantly fewer than caregivers of adults (41%).

### Use of Technology

When asked about their use of technology while caregiving, 39% of caregivers of children with special needs report having used at least one specified technology. Three in ten caregivers of children use an electronic organizer or calendar (30%), while about one in ten each use: an electronic sensor to detect safety problems (11%), a device that electronically transmits care information (9%), or a website or software to track the child's medical records (8%). They are far less likely than caregivers of adults to report use of an emergency response system, like Lifeline (2% vs. 14% caregivers of adults).

### Reaction to Caregiving-Related Policy

Of six potential national policies or programs to help caregivers and their care recipients, the preferred policy among caregivers of children, by far, is a caregiver tax credit of \$3,000 (62% net first or second most preferred). About one-third of caregivers of children prefer a voucher program that would pay them minimum wage for at least some of their time spent caregiving (35% first or second), while 23% prefer respite services. Caregivers of children are less likely to find an outside transportation service helpful (15% vs. 22% of caregivers of adults).

## K. Respondent Profile

Seven in ten caregivers of children with special needs are female, and on average, caregivers of children are 40.6 years old. Six in ten caregivers of children are white, 19% are Hispanic, 17% are African-American, and small percentages are Asian-American or another race. Caregivers of children are more often minority and younger than caregivers of adults.

About half of caregivers of children are married, and most (79%) have children or grandchildren under the age of 18 in their household, two and a half times the share of those caring for adults who do. This is not surprising since 65% of caregivers of children live with their recipient. Among caregivers of children who do not live with their care recipient, 42% have children or grandchildren under the age of 18 in their household.

**Figure 10: Profile of Respondents**

	Caregivers of Child Recipient Age 0 to 17 (n=173)	Caregivers of Adult Recipient Age 18 or older (n=1,296)
<b>Gender</b>		
Male	28%	35%
Female	72	65
<b>Age of Caregiver</b>		
18 to 34	35%*	19%
35 to 49	41*	28
50 to 64	17	38*
65 to 74	5	10*
75 or older	1	4*
<i>Mean age</i>	40.6	49.2*
<b>Race/Ethnicity of Caregiver</b>		
White	60%	73%*
African-American	17	12
Hispanic	19*	11
Asian-American	2	2
Other	1	2
<b>Marital Status</b>		
Married	53%	59%
Living with a partner	6	5
Single, never married	21	15
Separated, divorced	16	14
Widowed	4	6
<b>Children/Grandchildren &lt;Age 18 in Household</b>		
Yes	79%*	30%
No	21	70*

Caregivers of children with special needs tend to be less educated and have lower household income than caregivers of adults. One-third of caregivers of children have no more than a high school education and a similar proportion have completed college. Six in ten have less than \$50,000 in household income. About half are currently employed—but they are less likely than caregivers of adults to be working full time.

**Profile of Respondents (continued)**

	Caregivers of Child Recipient Age 0 to 17 (n=173)	Caregivers of Adult Recipient Age 18 or older (n=1,296)
<b>Education</b>		
Less than high school	13%*	5%
High school graduate	21	23
Some college	28	25
Technical school	4	2
College graduate	17	26*
Graduate school	15	19
<b>Household Income</b>		
Less than \$50,000 (net)	59%*	39%
Less than \$15,000	15*	7
\$15,000 to \$29,999	18	13
\$30,000 to \$49,999	24	18
Less than \$50,000, not fully specified	1	1
\$50,000 or more (net)	37	56*
\$50,000 to \$74,999	11	21*
\$75,000 to \$99,999	10	13
\$100,000 or more	15	20
\$50,000+, not fully specified	1	2
<i>Median Household Income</i>	<i>\$41,700</i>	<i>\$60,100</i>
<b>Current Employment Status</b>		
Working full time	35%	48%*
Working part time	18*	9
Retired	7	16*
Homemaker	14	10
Unemployed and looking for work	12	7
Disabled	8	5
Student	4	1
Other	2	3

A plurality of caregivers of children live in a suburban area (40%), but three in ten each live in urban or rural areas. Since the large majority live with their loved one, the living locations of child care recipients parallel those of their caregivers.

**Profile of Respondents** *(continued)*

	Caregivers of Child Recipient Age 0 to 17 (n=173)	Caregivers of Adult Recipient Age 18 or older (n=1,296)
<b>Caregiver Living Location</b>		
Urban	30%	28%
Suburban	40	38
Rural	26	32
<b>Care Recipient Living Location</b>		
Urban	31%	33%
Suburban	39	37
Rural	26	29
<b>Caregiver Service in Armed Forces</b>		
Served on active duty	7%	11%
Did not ever serve	92	89