CHILD CAREGIVING IN THE U.S.

PRESENTED TO:
Cancer Survivorship: Embracing the Future
October 6, 2006

Gail Gibson Hunt, President & CEO, National Alliance for Caregiving
NATIONAL ALLIANCE FOR CAREGIVING

WHO WE ARE

- Nonprofit coalition of 45 national groups which have come together around family caregiving
- Established in 1996 to support family caregivers and the professionals who work with them
- Purpose of Alliance: Conduct research; develop national programs; do policy analysis; strengthen coalitions; increase public awareness; work internationally
- Reputation: the go-to-place for family caregiving information
BACKGROUND

1998  First International Conference on Family Care (London)

2000  UK National Young Carers Summit (Manchester)

2002  Third International Conference on Family Care (Washington)

2005  Young Caregivers Conference—Alliance releases report

2006  Young Caregiver Summit

Alliance & MS Society
Method

- 2,000 households were surveyed in a telephone omnibus study to determine prevalence
- 80,000 households were screened by mail to identify households with child caregivers
- Households were re-screened by phone, and telephone interviews were conducted with:
  - 213 child caregivers
  - 250 children who are not caregivers
1 in 4 households have at least one 8-18 year old living there

That’s 28.4 million households

Among 109.4 million households in the U.S.

Child 8-18 years old lives in household

26%

Source: Current Population Survey 2002
3.2% of those households have at least one child caregiver

Among 28.4 million households with one or more children 8-18 years old

Sources: Child Caregiver Omnibus, 2003
Child Caregivers in the U.S., 2004
That’s over 900,000 households

With an average of 1.5 child caregivers per household

1.3 to 1.4 million 8- to 18-year-old child caregivers

Sources: Child Caregiver Omnibus, 2003
Child Caregivers in the U.S., 2004
Caregivers 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.

The care may include help with...

- Dressing or feeding
- Household chores or meals
- Keeping company or providing emotional support
- Taking medicine or communicating with doctors/nurses
- Shopping
- Paperwork, bills, or arranging outside services
- Moving around the house or getting around the community
- Bathing or using the bathroom

Source: Child Caregivers in the U.S., 2004
Who are the children who give care?

Caregivers are more likely to be in:
- lower income households
- single parent households

Source: Child Caregivers in the U.S., 2004
For whom are they caring?

- 72% Parent or grandparent
- Average age is 54
- 73% Female
- 64% Live in household
- 69% Can walk without help
- Top conditions include Alzheimer’s or dementia, heart/lung/kidney disease, arthritis, diabetes
- 4% have cancer

Source: Child Caregivers in the U.S., 2004
**What are caregivers’ responsibilities?**

*Do you help...*  

<table>
<thead>
<tr>
<th>Task Description</th>
<th>% Helping with each task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep [Name] company</td>
<td>96%</td>
</tr>
<tr>
<td>[Name] with household chores</td>
<td>85%</td>
</tr>
<tr>
<td>[Name] with grocery shopping</td>
<td>65%</td>
</tr>
<tr>
<td>Prepare meals for [Name]</td>
<td>63%</td>
</tr>
<tr>
<td>[Name] get in and out of beds or chairs</td>
<td>42%</td>
</tr>
<tr>
<td>[Name] get around the neighborhood/city</td>
<td>35%</td>
</tr>
<tr>
<td>[Name] take medicine or pills or shots</td>
<td>30%</td>
</tr>
<tr>
<td>Feed [Name]</td>
<td>27%</td>
</tr>
<tr>
<td>[Name] get dressed</td>
<td>19%</td>
</tr>
<tr>
<td>[Name] talk with doctors or nurses</td>
<td>17%</td>
</tr>
<tr>
<td>[Name] with paperwork or paying bills</td>
<td>17%†</td>
</tr>
<tr>
<td>Arrange for someone else to help [Name]</td>
<td>15%†</td>
</tr>
<tr>
<td>[Name] use the bathroom or diapers</td>
<td>8%</td>
</tr>
<tr>
<td>[Name] bathe or shower</td>
<td>8%</td>
</tr>
</tbody>
</table>

† (Among those 12+ years of age)

Source: Child Caregivers in the U.S., 2004
Number of Caregiving Tasks

**ADLs**
- None: 42%
- One: 30%
- Two: 16%
- Three to five: 12%

**IADLs Out of five total for 8-11 year olds**
- None: 8%
- One: 12%
- Two: 34%
- Three to five: 46%

**IADLs Out of six total for 12+ year olds**
- None: 3%
- One: 10%
- Two: 24%
- Three to six: 63%

Source: Child Caregivers in the U.S., 2004
Time Usage – Chores & Responsibilities

In a normal week, how much time do you spend…

- Sweeping, vacuuming, or dusting: 84% * Caregivers, 72% Non-Caregivers
- Shopping for groceries: 68% * Caregivers, 55% Non-Caregivers
- Washing dishes: 63% Caregivers, 56% Non-Caregivers
- Doing laundry: 57% * Caregivers, 48% Non-Caregivers
- Making dinner: 58% * Caregivers, 45% Non-Caregivers
- Working at a job (Among those 12+ years of age): 35% Caregivers, 31% Non-Caregivers
- Taking care of brothers or sisters (Among those with other children in the household – in addition to the care receiver if s/he is a sibling): 80% * Caregivers, 64% Non-Caregivers

* Significant difference (95% confidence)

Source: Child Caregivers in the U.S., 2004
Behavior Problems Overview

Using an established Behavior Problems Index, parents were asked whether selected behavior problems had occurred in the past three months…

- Child caregivers demonstrate more anxious/depressed behavior than non-caregivers
- 12-18 year old caregivers demonstrate more antisocial behavior than non-caregivers of the same age

Source: Child Caregivers in the U.S., 2004
Caregiver Behavior Problems

Anxiety/Depression

- Feeling no one loves them
- Feeling worthless or inferior (8-11 year olds only)
- Sudden mood changes (12-18 year olds only)

Source: Child Caregivers in the U.S., 2004
Anxious or Depressed Behavior

*In the past three months, has this been often true, sometimes true, or not true of [CHILD]*?

<table>
<thead>
<tr>
<th>Behavior</th>
<th>8-11 Year Olds</th>
<th>12-18 Year Olds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worries too much</td>
<td>N/A</td>
<td>61%</td>
</tr>
<tr>
<td>Has sudden mood changes</td>
<td>58%</td>
<td>61% **</td>
</tr>
<tr>
<td>Is too fearful or anxious</td>
<td>44%</td>
<td>35%</td>
</tr>
<tr>
<td>Is unhappy, sad, or depressed</td>
<td>41%</td>
<td>41%</td>
</tr>
<tr>
<td>Feels that no one loves him/her</td>
<td>36% *</td>
<td>23% *</td>
</tr>
<tr>
<td>Feels worthless or inferior</td>
<td>35% *</td>
<td>29%</td>
</tr>
</tbody>
</table>

* Significant difference (95% confidence)
** Marginal difference (90% confidence)

Source: Child Caregivers in the U.S., 2004
Caregiver Behavior Problems

**Antisocial Behavior** (12-18 year olds)

- Bullying/cruelty
- Trouble getting along with teachers
- Hanging out with kids who get in trouble
- Disobedience at school

Source: Child Caregivers in the U.S., 2004
**Antisocial Behavior**

*In the past three months, has this been often true, sometimes true, or not true of [CHILD]?

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<thead>
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<th>Behavior</th>
<th>8-11 Year Olds</th>
<th>12-18 Year Olds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cheats or tells lies</td>
<td>38%</td>
<td>44%</td>
</tr>
<tr>
<td>Not sorry after misbehaving</td>
<td>36%</td>
<td>33%</td>
</tr>
<tr>
<td>Bullies, or is cruel or mean to others</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td>Is disobedient at school</td>
<td>12%</td>
<td>20%</td>
</tr>
<tr>
<td>Breaks things on purpose</td>
<td>11%</td>
<td>N/A</td>
</tr>
<tr>
<td>Has trouble getting along with teachers</td>
<td>9%</td>
<td>27%</td>
</tr>
<tr>
<td>Hangs out with kids who get in trouble</td>
<td>N/A</td>
<td>17%</td>
</tr>
</tbody>
</table>

* Significant difference (95% confidence)
** Marginal difference (90% confidence)

Source: Child Caregivers in the U.S., 2004
Other Negative Impacts of Caregiving

How often do you feel...

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Non-Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have time for yourself</td>
<td>38%</td>
<td>47% **</td>
</tr>
<tr>
<td>It’s no use letting your feelings show (boys)</td>
<td>26% *</td>
<td>11%</td>
</tr>
</tbody>
</table>

* Significant difference (95% confidence)
** Marginal difference (90% confidence)

Source: Child Caregivers in the U.S., 2004
School Problems

How often are you / How often do you...

<table>
<thead>
<tr>
<th>Issue</th>
<th>Caregivers</th>
<th>Non-Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too worried to concentrate on school work</td>
<td>58%</td>
<td>56%</td>
</tr>
<tr>
<td>Miss turning in homework</td>
<td>41%</td>
<td>36%</td>
</tr>
<tr>
<td>Absent from school</td>
<td>32%</td>
<td>33%</td>
</tr>
<tr>
<td>Kept from doing school work by other</td>
<td>31%</td>
<td>32%</td>
</tr>
<tr>
<td>responsibilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fall asleep in class</td>
<td>19%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Source: Child Caregivers in the U.S., 2004
Caregivers’ School Problems

How often has helping [Name]...

% Sometimes or a lot

- Made you miss a school or after-school activity: 20%
- Kept you from school work: 15%
- Made you miss homework: 8%

Source: Child Caregivers in the U.S., 2004
Who is affected the most?

Children who perform at least one ADL
- Perceive more responsibility
- Feel more that people expect too much from them
- More likely to feel it is no use letting feelings show
- More mood changes
- More school absenteeism

Caregivers who live with the care receiver
- Anxiety and antisocial behavior is more pronounced (for 8-11 year olds)
- More time is spent giving care
- Days are less productive
- Miss submitting homework more often

Source: Child Caregivers in the U.S., 2004
Who is affected the most?

Minority children

- Less likely to say someone else helps with caregiving
- More likely to feel it is no use letting feelings show
- More feel sad
- Parents more likely to report anxiety and antisocial behavior (for 12-18 year olds)

Source: Child Caregivers in the U.S., 2004
### Positive Impacts of Caregiving

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Caregivers</th>
<th>Non-Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appreciated for the help you give</td>
<td>64% *</td>
<td>53%</td>
</tr>
<tr>
<td>People expect too much from you</td>
<td>12%</td>
<td>19% *</td>
</tr>
<tr>
<td>Angry about all you have to do</td>
<td>8%</td>
<td>13% **</td>
</tr>
</tbody>
</table>

* Significant difference (95% confidence)
** Marginal difference (90% confidence)

Source: Child Caregivers in the U.S., 2004
Where to get the study:

http://www.caregiving.org