

CHILD CAREGIVING IN THE U.S.

PRESENTED TO:

Cancer Survivorship: Embracing the Future

October 6, 2006

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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

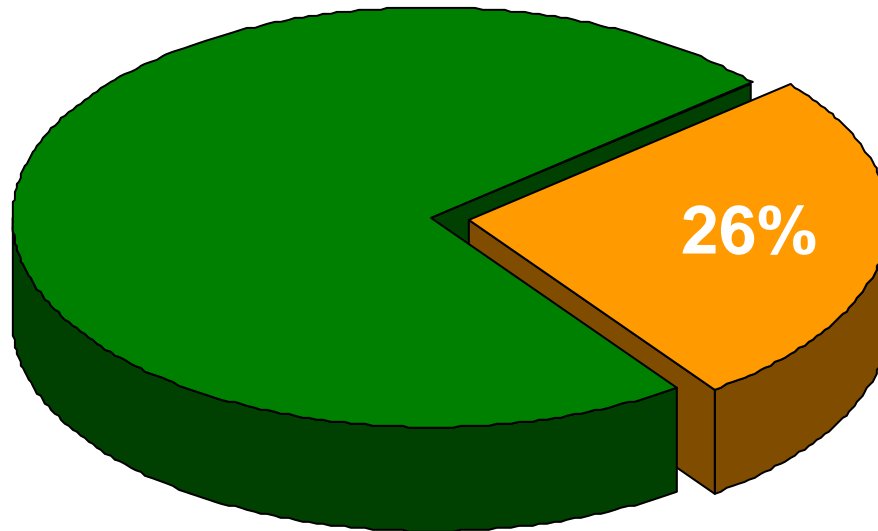
Method

- 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

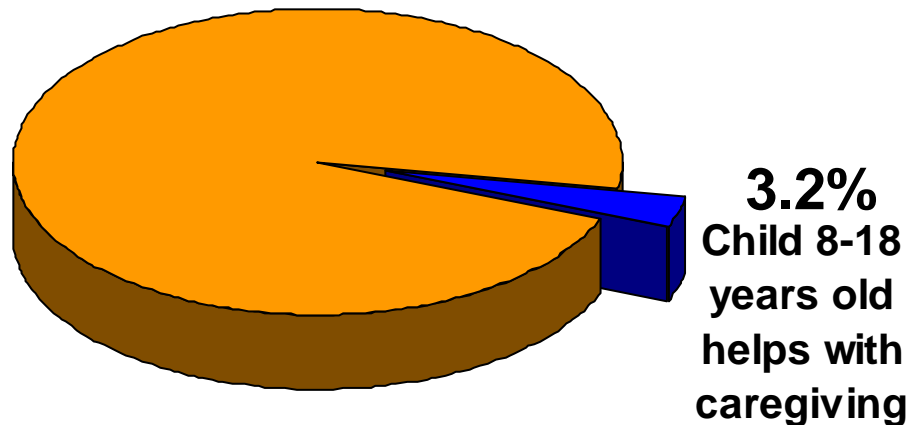
*Among 109.4 million households
in the U.S.*



**Child 8-18
years old
lives in
household**

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

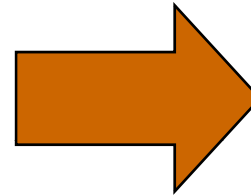


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Sources: Child Caregiver Omnibus, 2003
Child Caregivers in the U.S., 2004

That's over 900,000 households

With an average
of 1.5 child
caregivers
per household



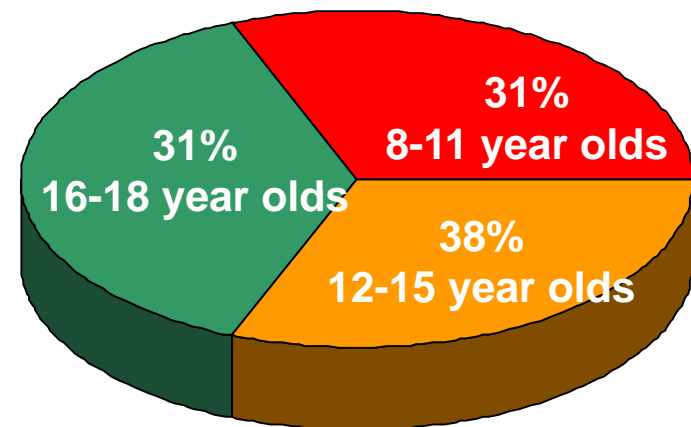
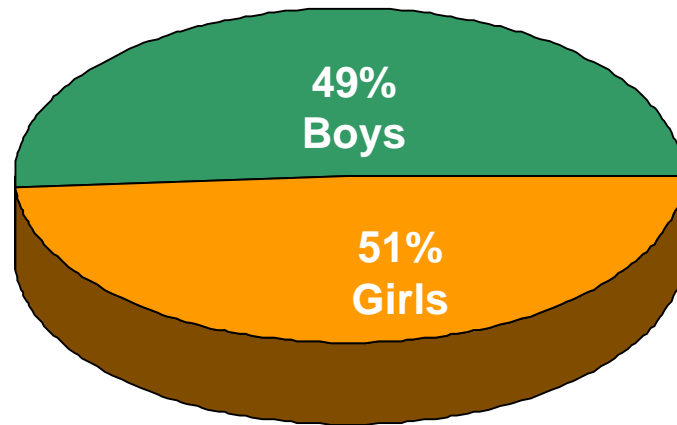
1.3 to 1.4
million
8- to 18-year-old
child
caregivers

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

Who are the children who give care?



Caregivers are more likely to be in...

- lower income households
- single parent households

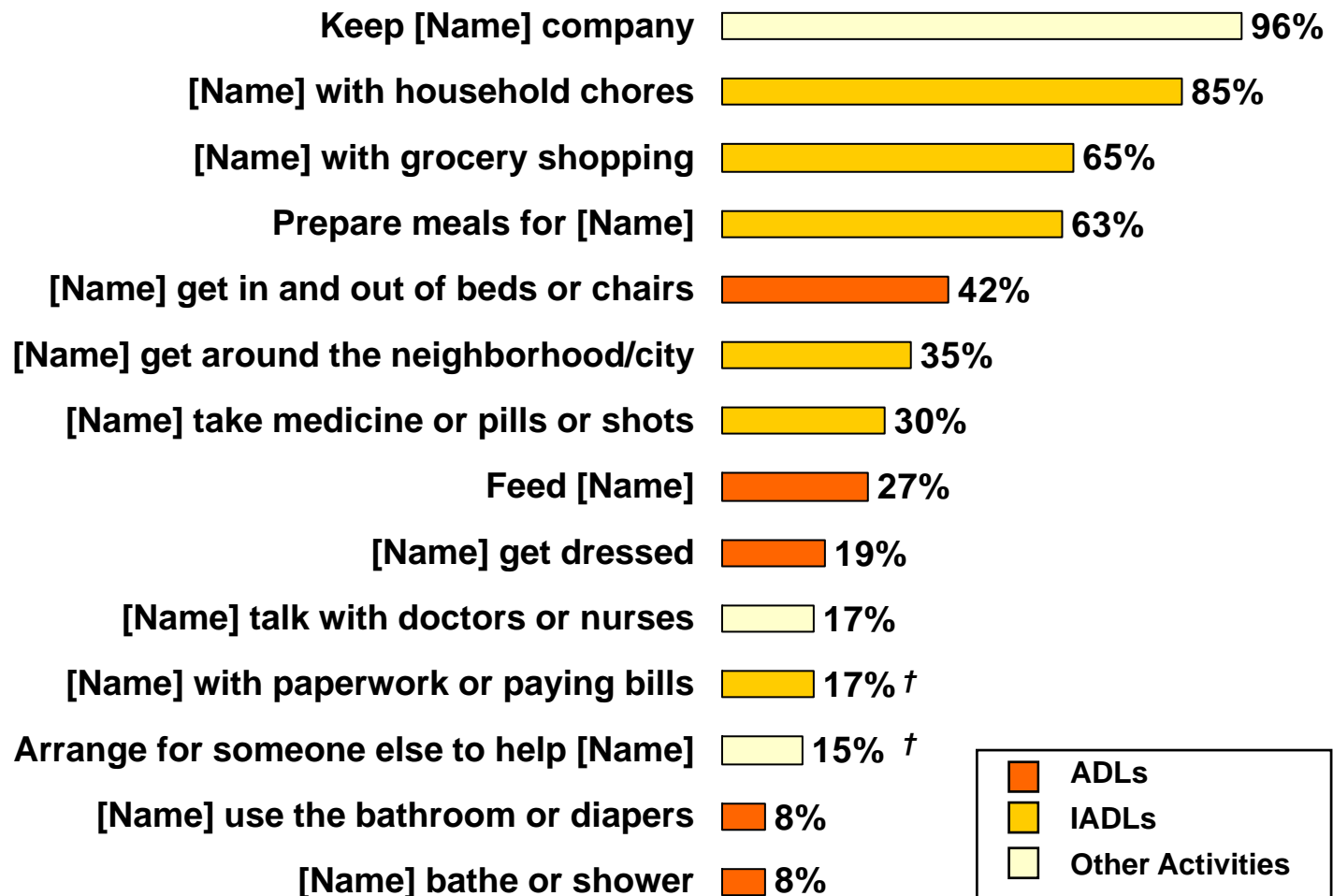
For whom are they caring?

- 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

What are caregivers' responsibilities?

Do you help...

% Helping with each task



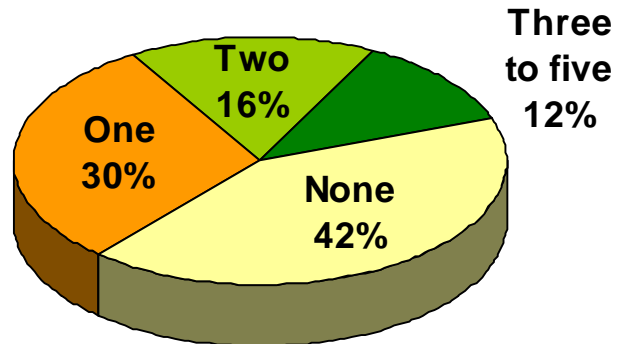
† (Among those 12+ years of age)

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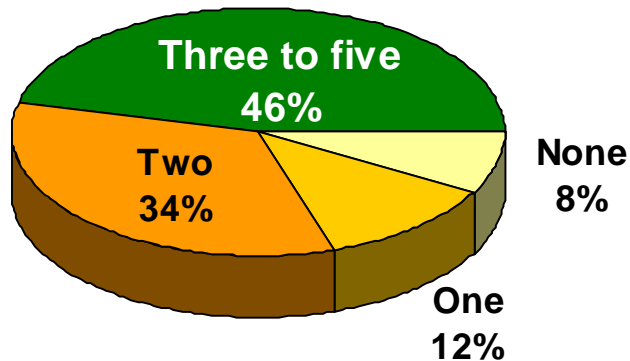
Source: Child Caregivers in the U.S., 2004

Number of Caregiving Tasks

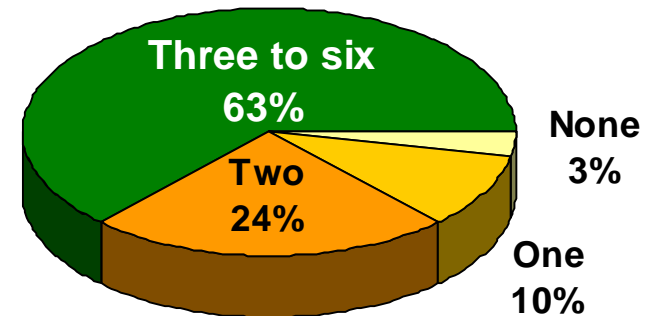
ADLs



IADLs Out of five total for 8-11 year olds

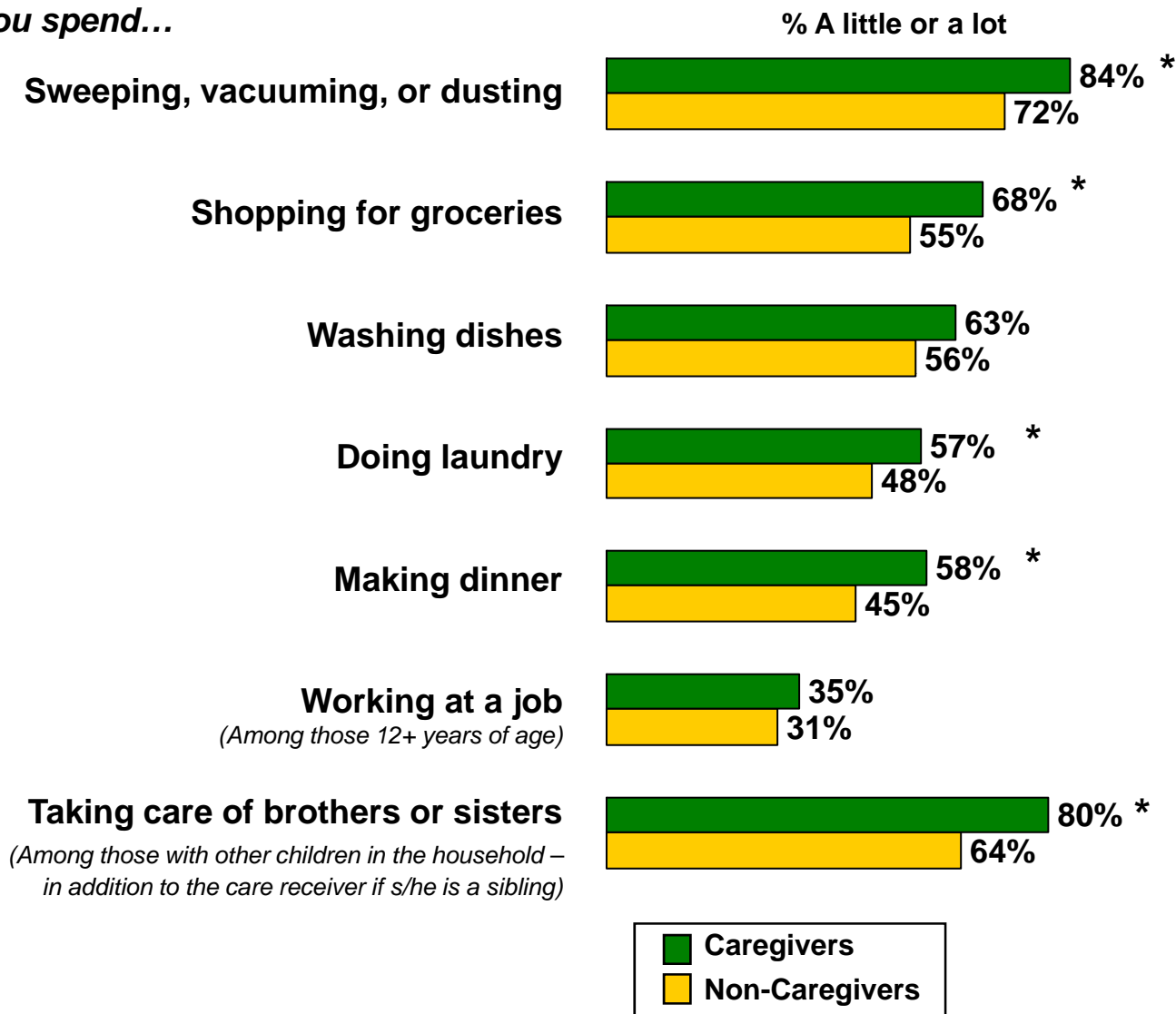


IADLs Out of six total for 12+ year olds



Time Usage – Chores & Responsibilities

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



* 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

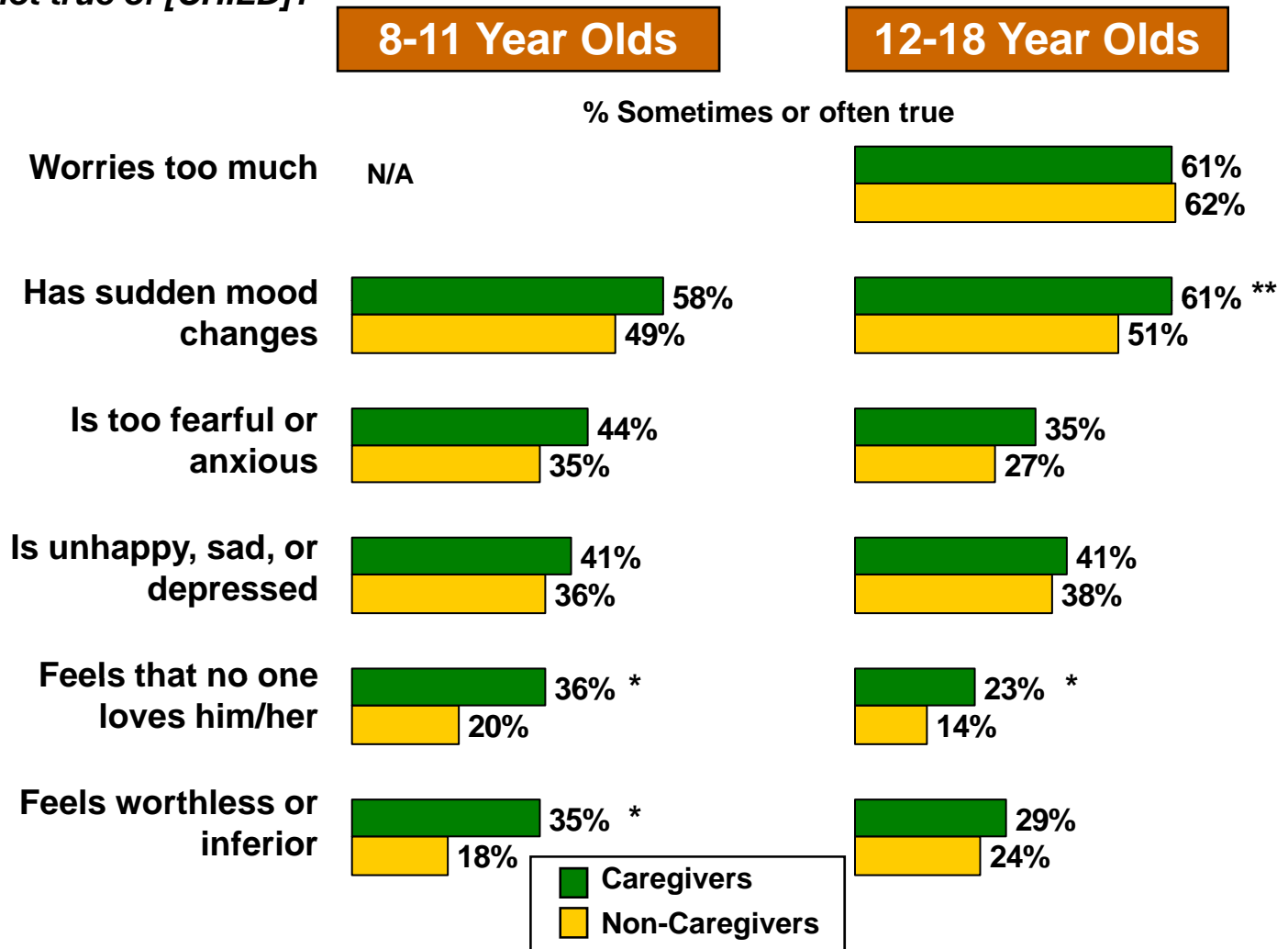
Caregiver Behavior Problems

Anxiety/Depression

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

Anxious or Depressed Behavior

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



* 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**

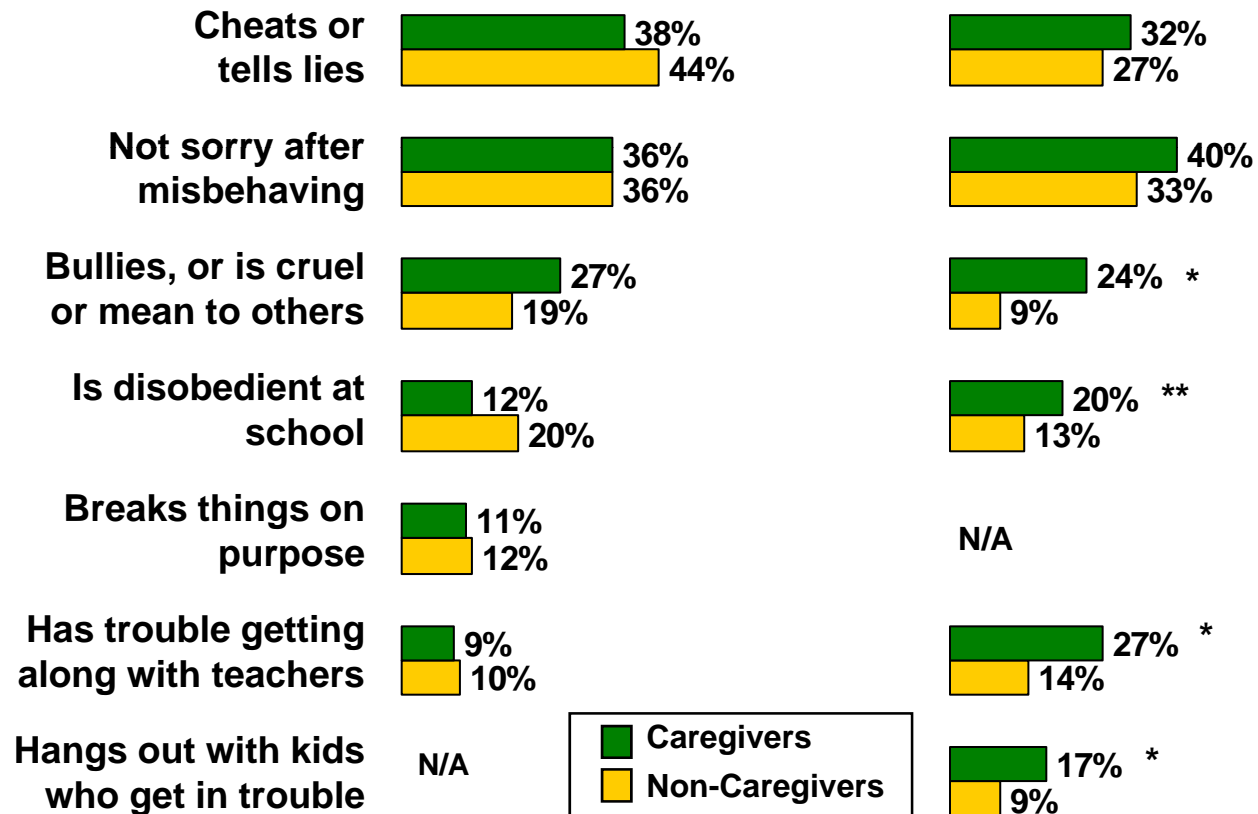
Antisocial Behavior

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

8-11 Year Olds

12-18 Year Olds

% Sometimes or often true



* 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...

Caregivers

Non-Caregivers

% A lot

You have time for yourself

38%

47% **

It's no use letting your
feelings show

(boys)

26% *

11%

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* 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...

% Sometimes or a lot

Too worried to concentrate on
school work



Miss turning in homework



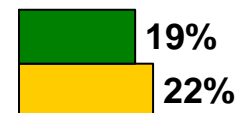
Absent from school



Kept from doing school work by
other responsibilities



Fall asleep in class



Caregivers
Non-Caregivers

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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%

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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

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)

Positive Impacts of Caregiving

How often do you feel...

Caregivers

Non-Caregivers

% A lot

Appreciated for the help you give

64% *

53%

People expect too much from you

12%

19% *

Angry about all you have to do

8%

13% **

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* 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>