

# **CHILD CAREGIVING IN THE U.S.**

**PRESENTED TO:**

**Cancer Survivorship: Embracing the Future**

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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

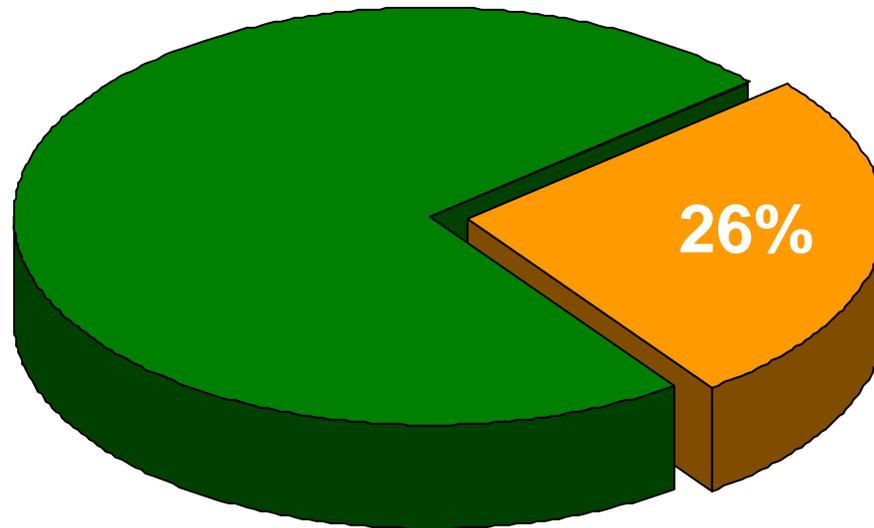
# Method

- **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

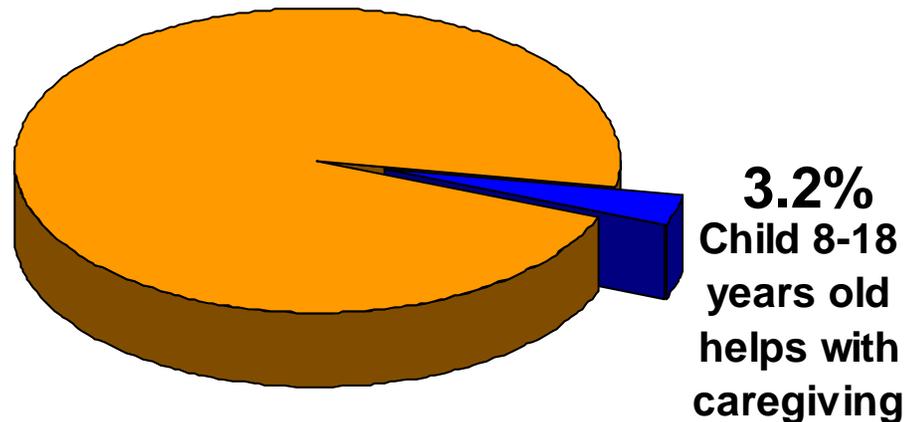
*Among 109.4 million households  
in the U.S.*



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

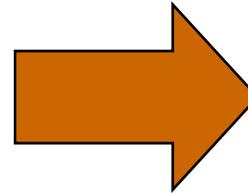
# 3.2% of those households have at least one child caregiver

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



# That's over 900,000 households

With an average  
of 1.5 child  
caregivers  
per household



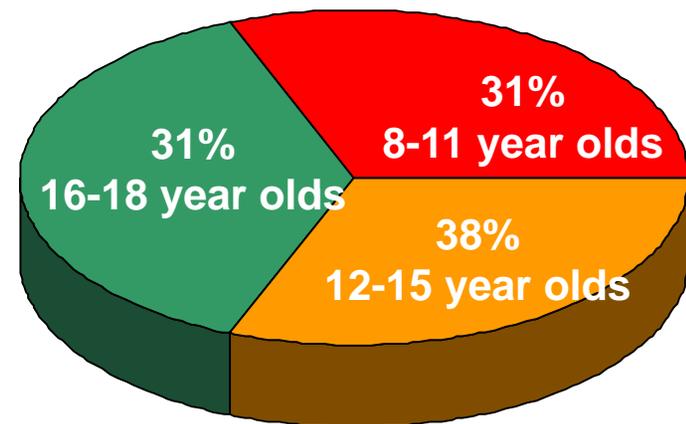
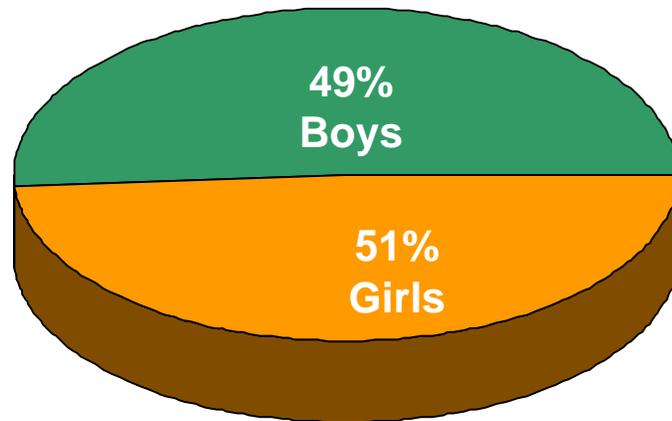
1.3 to 1.4  
million  
8- to 18-year-old  
child  
caregivers

# 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

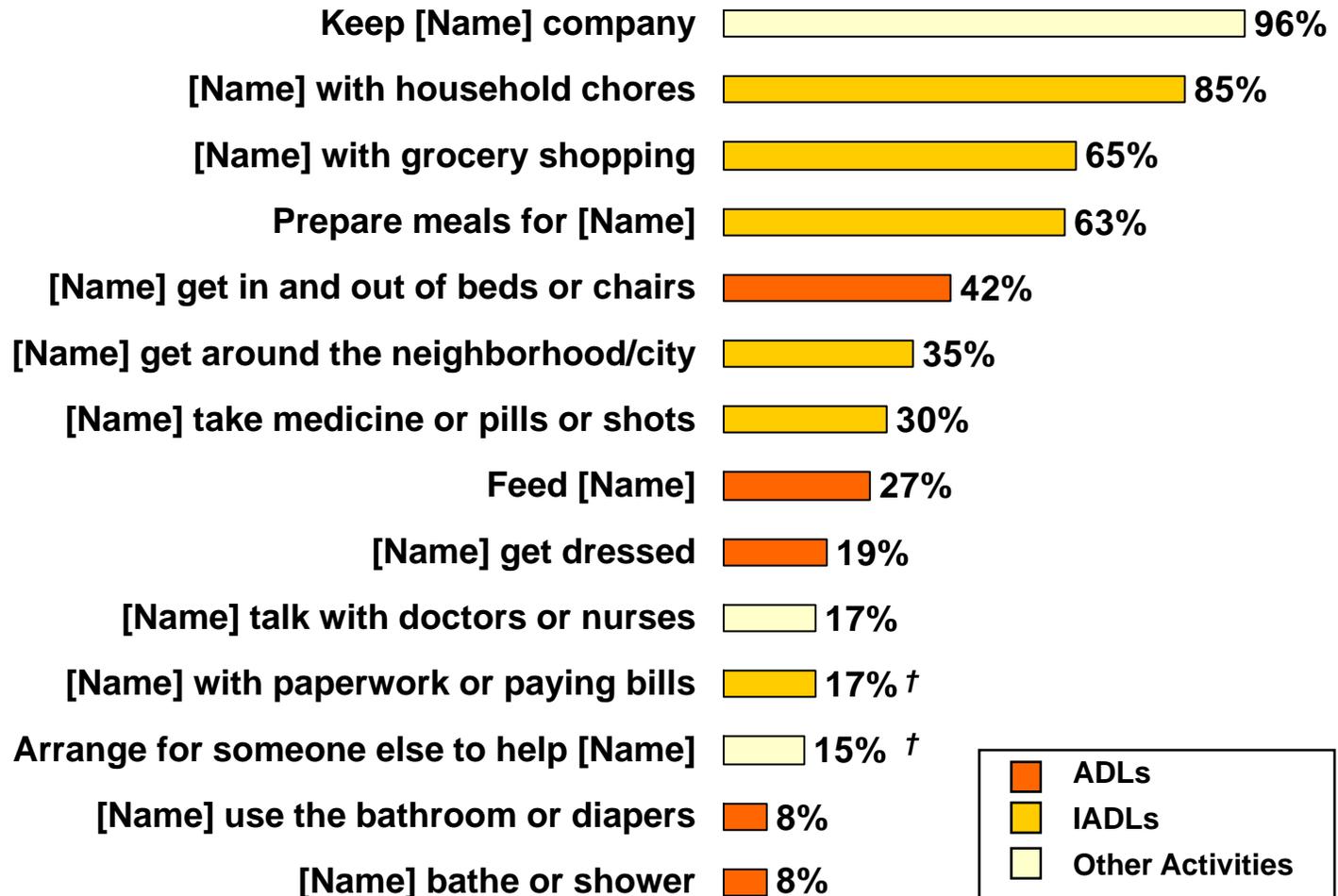
# For whom are they caring?

- 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

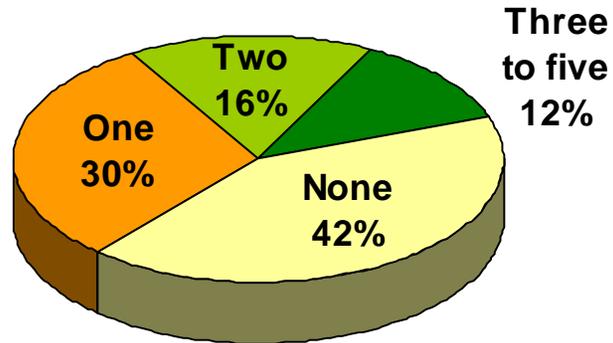


† (Among those 12+ years of age)

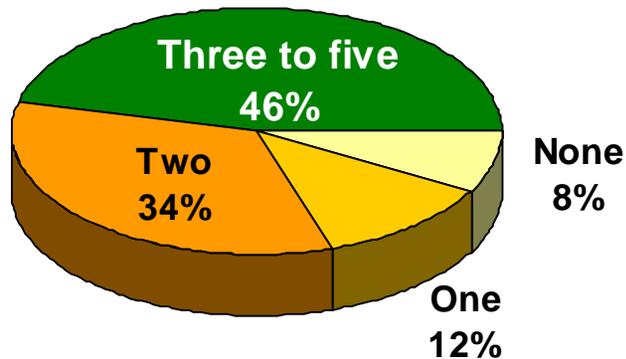
Source: Child Caregivers in the U.S., 2004

# Number of Caregiving Tasks

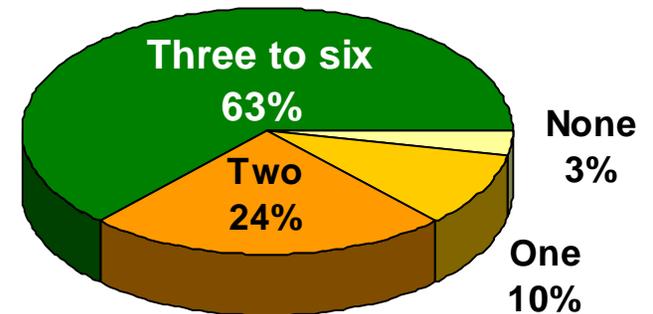
## ADLs



## IADLs Out of five total for 8-11 year olds

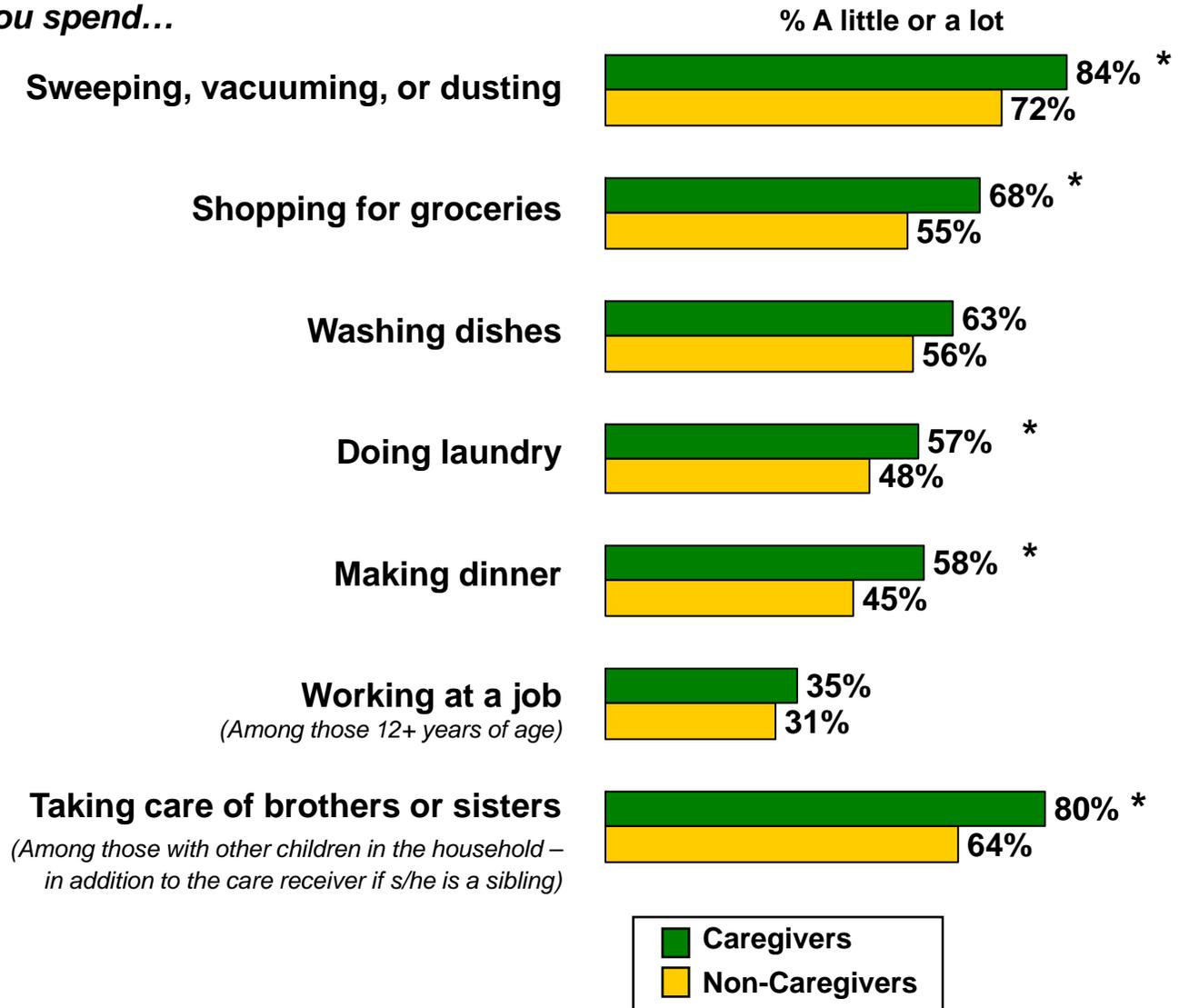


## IADLs Out of six total for 12+ year olds



# 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

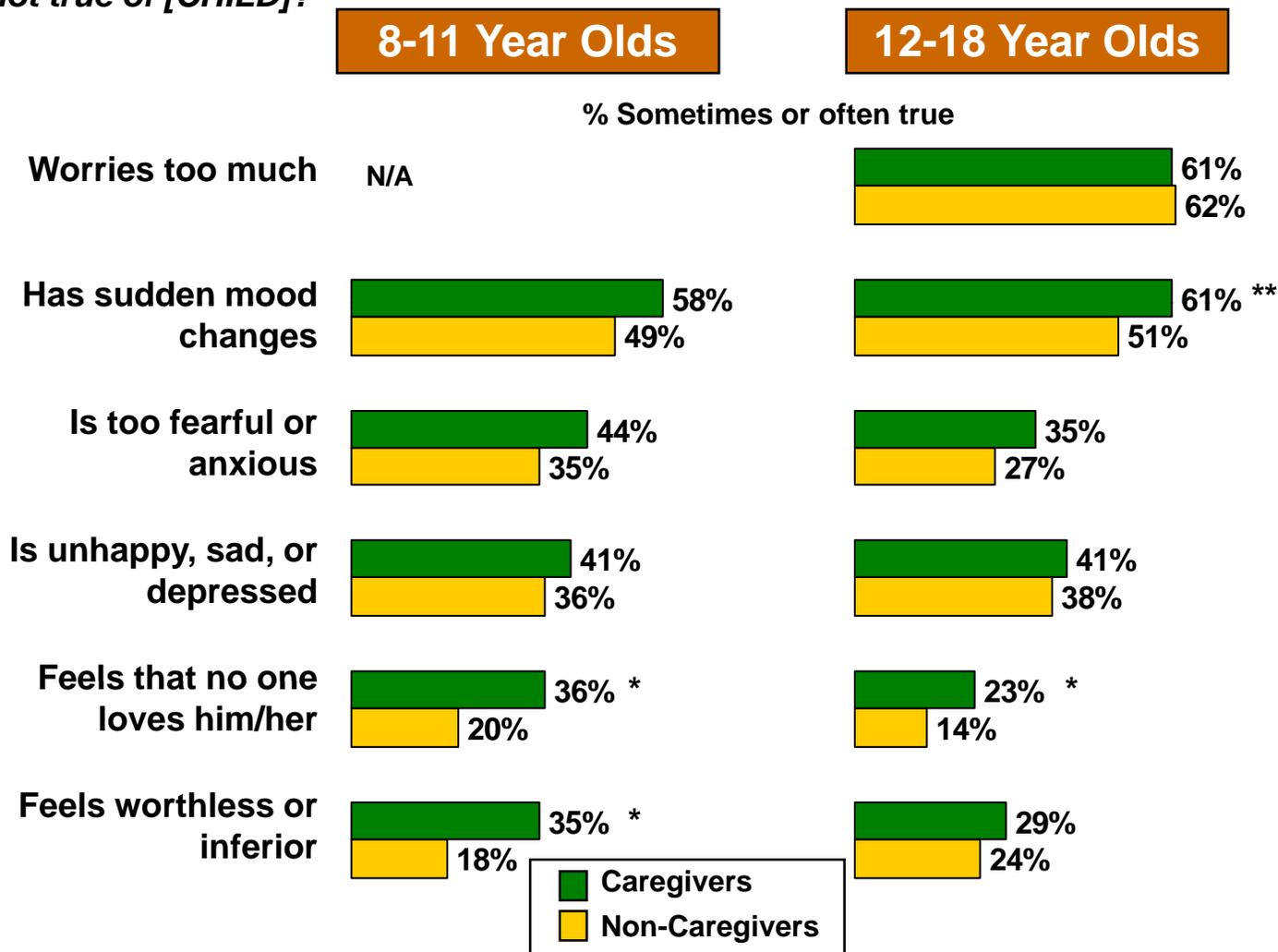
# Caregiver Behavior Problems

## 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

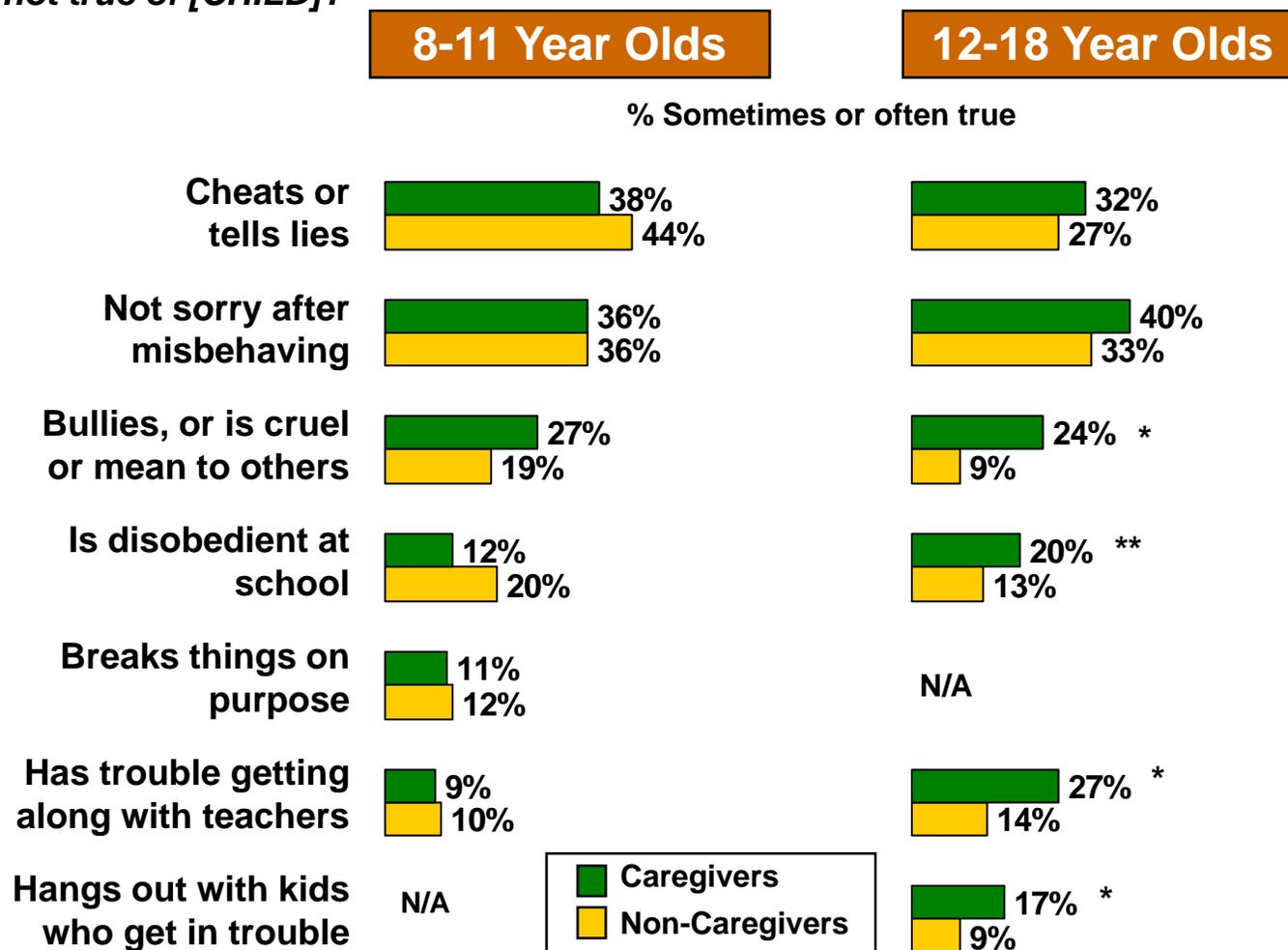
# Caregiver Behavior Problems

## Antisocial Behavior (12-18 year olds)

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

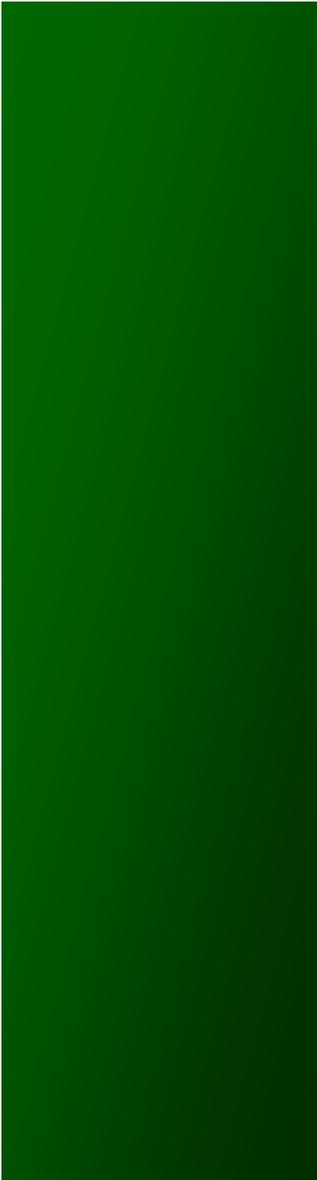
# Antisocial Behavior

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



\* Significant difference (95% confidence)

\*\* Marginal difference (90% confidence)



# 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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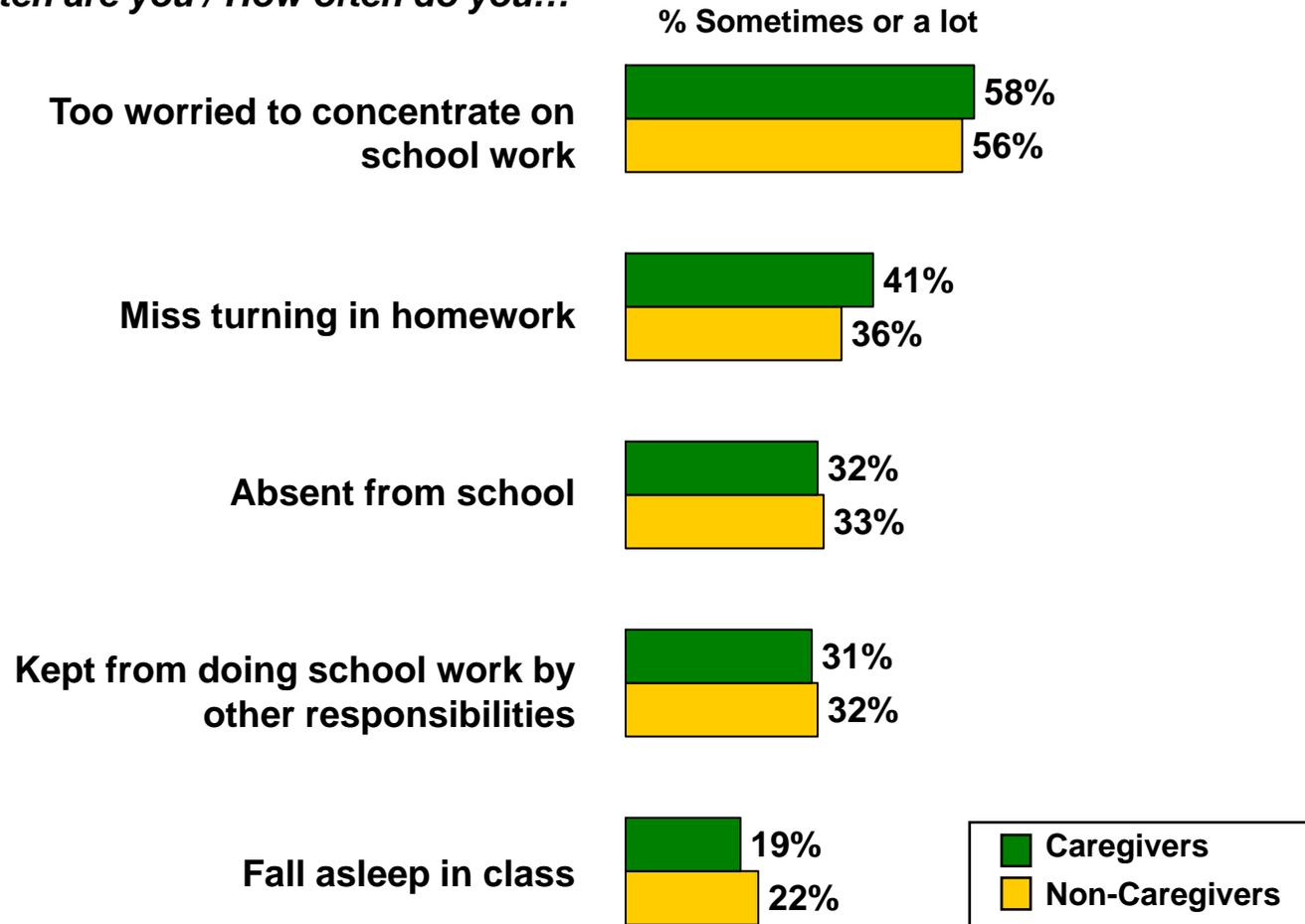
\* Significant difference (95% confidence)

\*\* Marginal difference (90% confidence)

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

# School Problems

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



# 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>**

**National Alliance  
for Caregiving**