

Trends in Family Caregiving and Why It Matters

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Purpose

- Provide an overview of trends in disability and informal caregiving
 - Type of disability accommodation
 - Type of assistance received
 - Characteristics of recipients and caregivers
- Provide an example of why support for informal caregivers is important for policymakers to consider

Sources

Staying the Course: Trends in Family Caregiving

http://assets.aarp.org/rgcenter/il/2005_17_caregiving.pdf

Does High Caregiver Stress Lead to Nursing Home Entry?

<http://aspe.hhs.gov/daltcp/reports/2007/NHentry.pdf>



Background for trends

- Informal caregivers, mostly close family, are the foundation of LTC for older persons
- Between mid 1980s and mid 1990s
 - Use of formal, paid care increased
 - Number of family caregivers declined
 - More were sole informal caregiver for persons with greater disability
- Demographic trends suggest future decline in available family
- Medicare formal care changed in the late 90s

Data

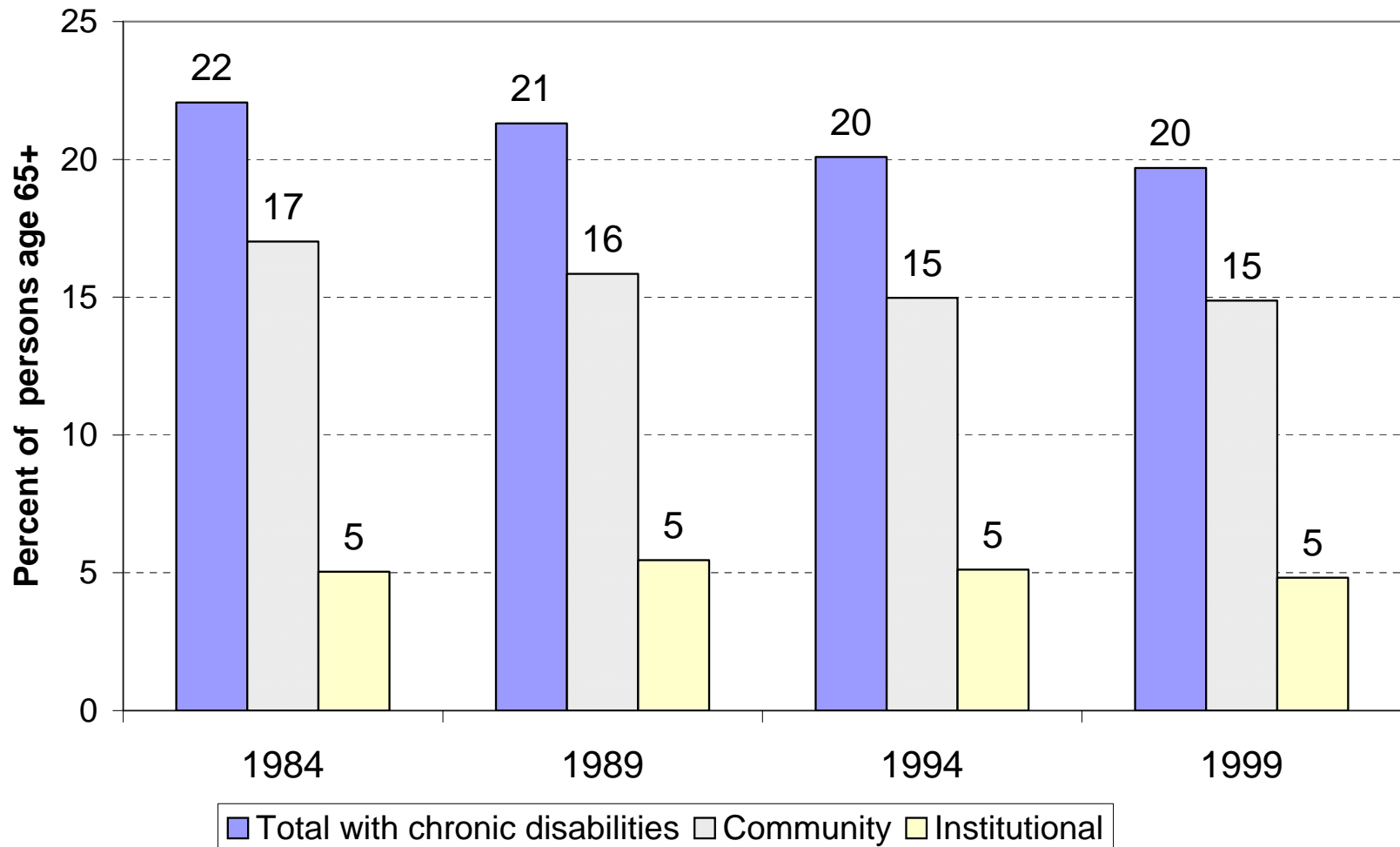
- National Long Term Care Survey 1984-1999
- Nationally representative of Medicare elderly
- Provides consistent data on
 - disability and care arrangements
 - recipient and family caregiver characteristics
 - primary informal caregivers



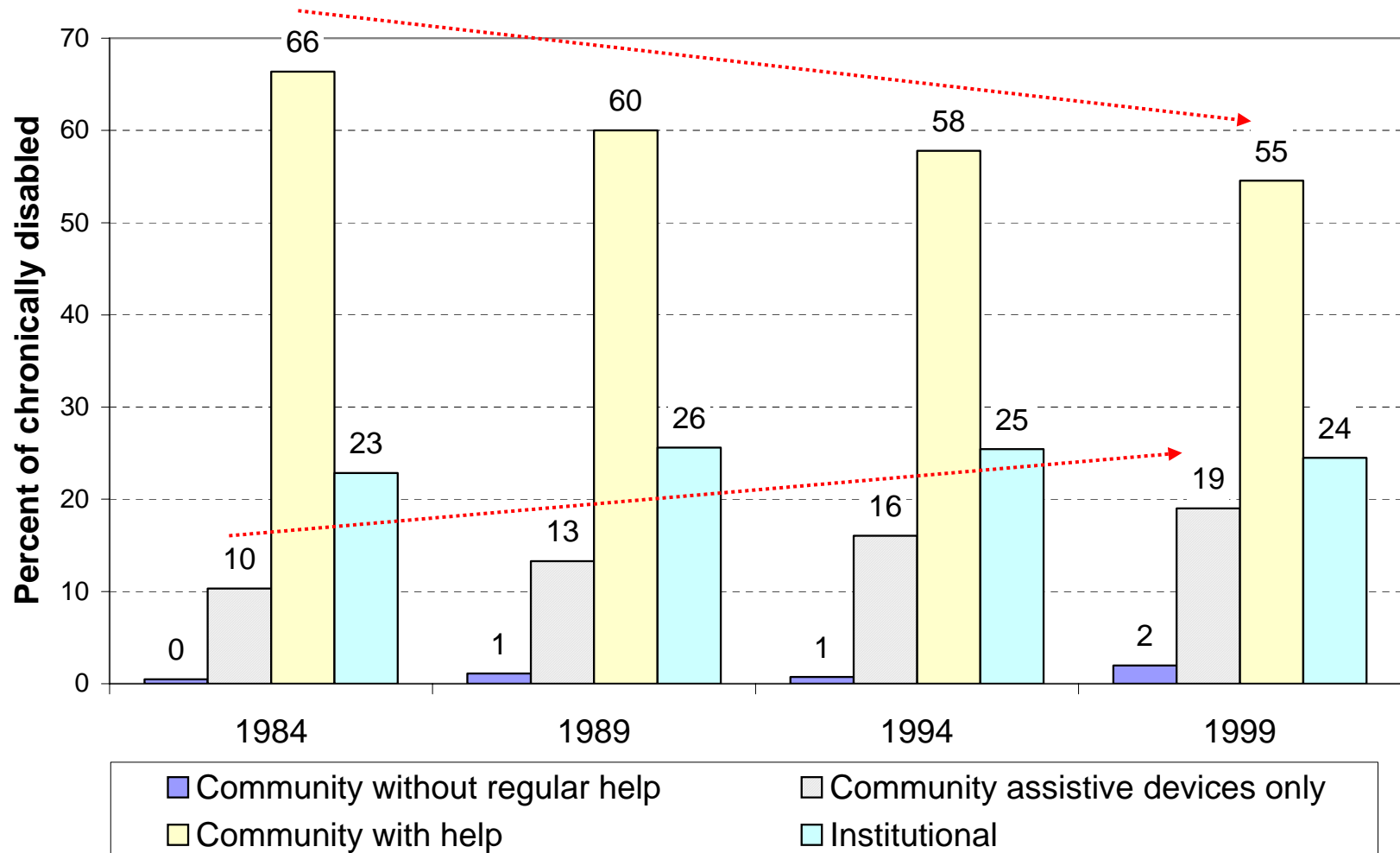
Disability Definition

- Uses help or assistive devices to perform any of 6 ADLs (personal care)
- Unable to do any of 8 IADLs (independent living activities) because of health or disability
- Chronic: Lasting at least 90 days

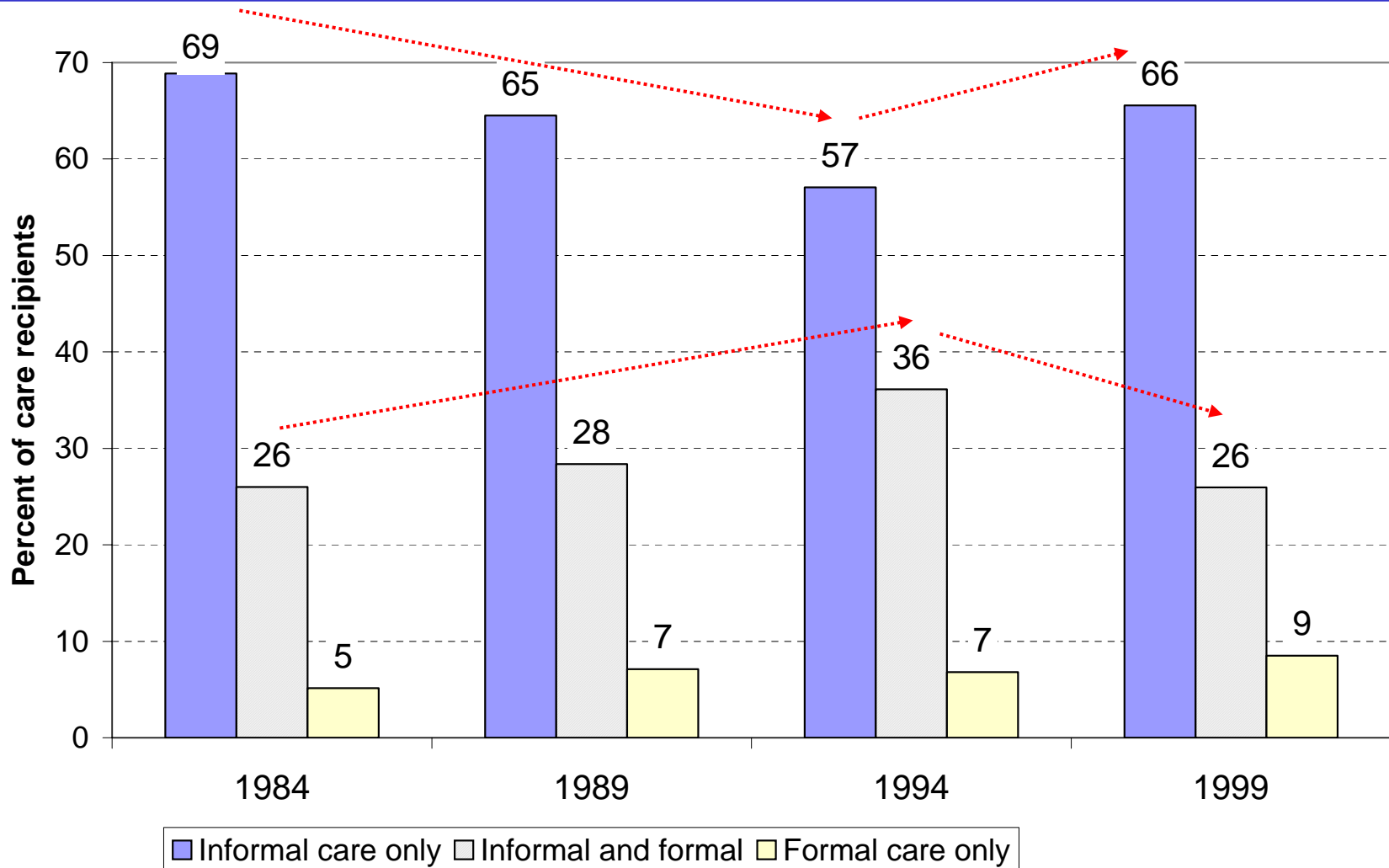
Chronic Disability Trend 1984-1999



Managing Disability, 1984-1999



Sources of Community Care, 1984-1999



Profile: Chronically Disabled Elders, 1999

	Number of persons (000s)	Percent of persons	Change 1994-1999
All	6,785	100	132
65-74	1,668	25	-4 **
75-84	2,826	42	2
85+	2,291	34	3 **
< 3 ADLs	3,357	49	-3 **
3+ ADLs	3,428	51	3 *
Has spouse or child	5,780	85	4 **
Spouse and child	1,927	28	0
Spouse only	218	3	0
Child only	3,636	54	4 **
Neither spouse nor child	1,005	15	-4 **

Note: ** (*) = significant at the 5% (10%) significance level



Messages

- Despite downward trends in disability help, no evidence of reduced family caregiving
- Cautions
 - Formal care fell most for highly disabled persons and persons with only a spouse
 - Age of family caregivers and age and disability level of recipients continued to increase
 - ◆ Suggests greater caregiver burden over time
 - ◆ Particularly worrisome for spouses and those caring for highly disabled persons
 - Potential unmet need among persons receiving care—or their caregivers—not addressed

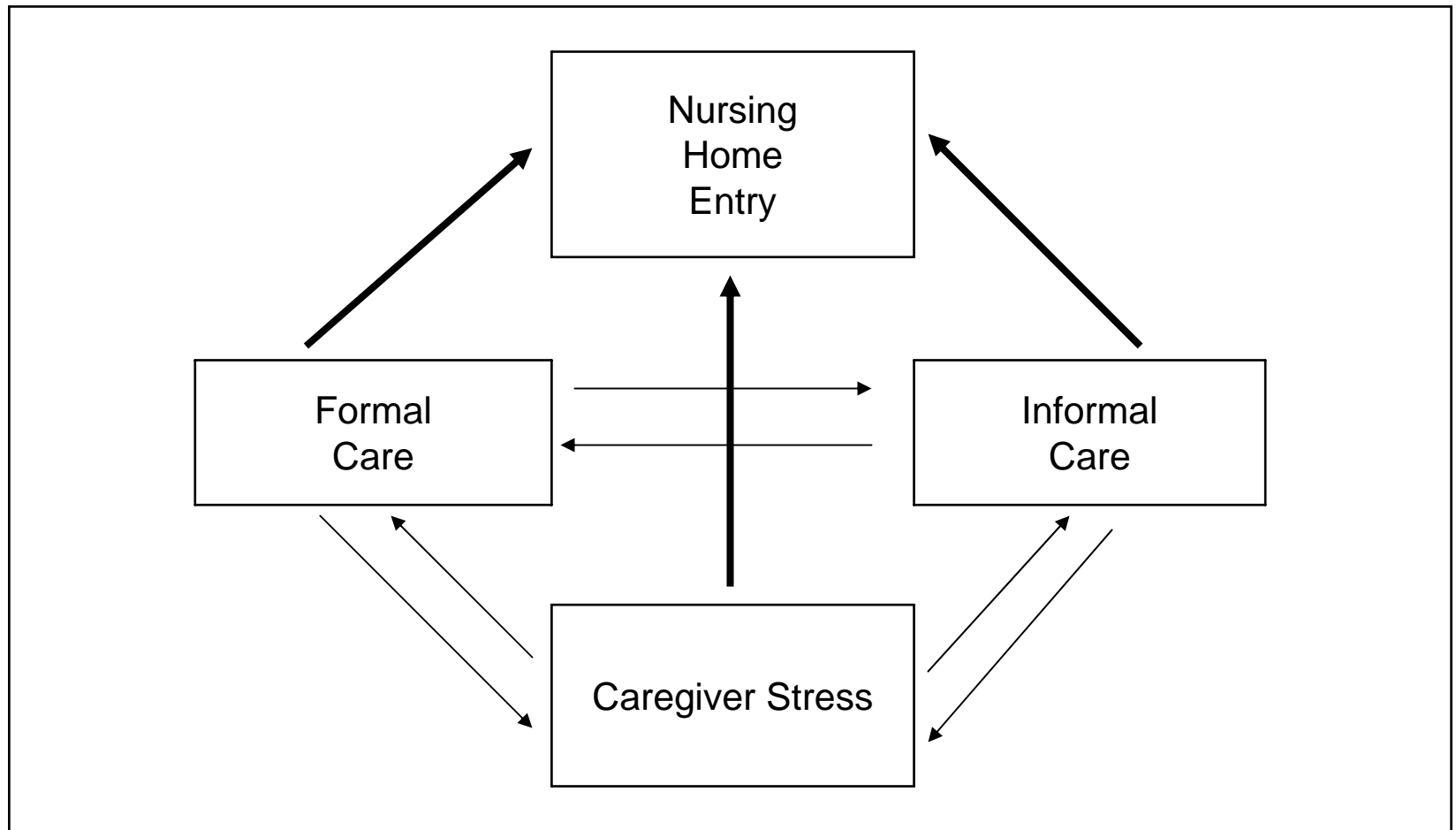
Nursing Home Study Aims

- Estimate the impact of caregiver stress on admission to longer nursing home stays, incorporating family decisions on formal care and informal care
- Simulate impacts of reducing caregiver stress (overall and by source of stress) on nursing home entry

Profile of Primary Informal Caregivers

- Predominantly women (66%)
- Nearly half are 65+; 31% are under 55
- 38% are spouses; 49% are children
- 1 in 3 say they're in fair or poor health
- Nearly 80% say caregiving is rewarding
- Nearly 60% rate their stress as low—between 1 and 3 on a scale of 1-10
- 19% rate their stress level as 6 or higher

Conceptual Model



Estimated Impacts on NH Entry

	Within 1 year	Within 18 months	Within 2 years
ln(formal care hours)	-0.005	0.003	0.015
ln(informal care hours)	-0.040	-0.062	-0.036
Caregiver reports high stress	0.120 *	0.165 **	0.172 **

** (*) $P > |t| \leq .05(.10)$

Key Factors Contributing to High Stress

	Marginal effect	P > z
Caregiving is a physical strain ^a	0.222	0.00
Caregiver's sleep disturbed 3+ times last week	0.104	0.04
Recipient had behavior problems 3+ times last	0.101	0.00
Caregiving is a financial hardship ^a	0.089	0.05
Caregiver is recipient's child	0.088	0.01

^a Caregiver's rating is 3+ on a scale of 1 to 5.

Simulation Results

NH Entry within 2 Years

	Predicted likelihood	Change
Baseline probability of nursing home entry	12.6	—
If all high stress eliminated	9.3	- 3.3
Impact of reducing key sources of stress		
If physical strain eliminated	11.0	- 1.5
If financial hardship eliminated	11.9	- 0.7
If both eliminated	10.7	- 1.9

Summary of Findings

- Having a highly stressed caregiver increases the likelihood of a longer NH stay within 2 years by 17 percentage points.
- Eliminating high caregiver stress could reduce expected admissions within 2 years *among persons with caregivers* by about 25%
- Eliminating physical and financial strain could reduce the proportion of caregivers with high stress to 8%, which could reduce NH admissions *among persons with caregivers* by 15%

Implications

- Caregiver support policies that address major sources of stress may significantly reduce NH entry
- Most obvious policy handles to reduce stress are physical and financial strain of caregiving
- “Dose” required to sufficiently reduce stress remains to be determined—as does cost
- Additional research needed
 - To understand efficacy of particular policies in reducing stress
 - To better understand role of caregiver stress in other health care spending for both recipients and caregivers
 - On links between formal care, informal care, and caregiver stress