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Health Issues for Aging Populations: Family Caregiving

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Management

Agenda for Talk

- What is family caregiving?
- Caregiving by the numbers
- Trends in family caregiving
- Caregiver issues
- “Hot” Topics

What is Family Caregiving?

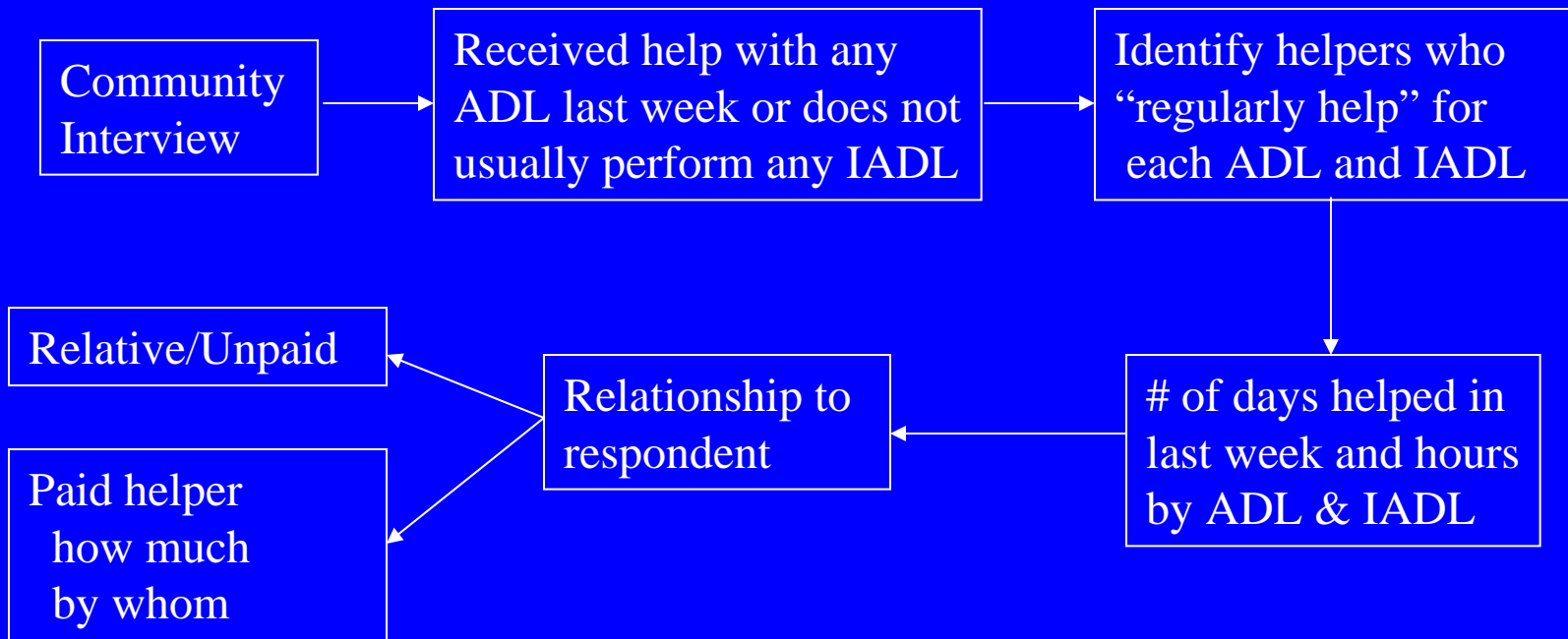
“Caregiver” – MESH Term

“Persons who provide care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients, etc.”

2004 National Alliance for Caregiving Survey

“In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing”.

Caregiving: NLTCS



Family Caregivers: Two Surveys

Survey	NLTCS*	NAC
Number (million)	4.6-5.6	44.1
Age (mean)	63	46
Female (%)	67%	61%
Spouse/Child Caregiver	79%	12%
Employed	32%	59%
Average weekly hours	30	21

*Sources: 1999 National Long-Term Care Survey/Informal Caregivers Survey
And National Alliance for Caregiving*

*Note: demographics and characteristics for primary caregivers

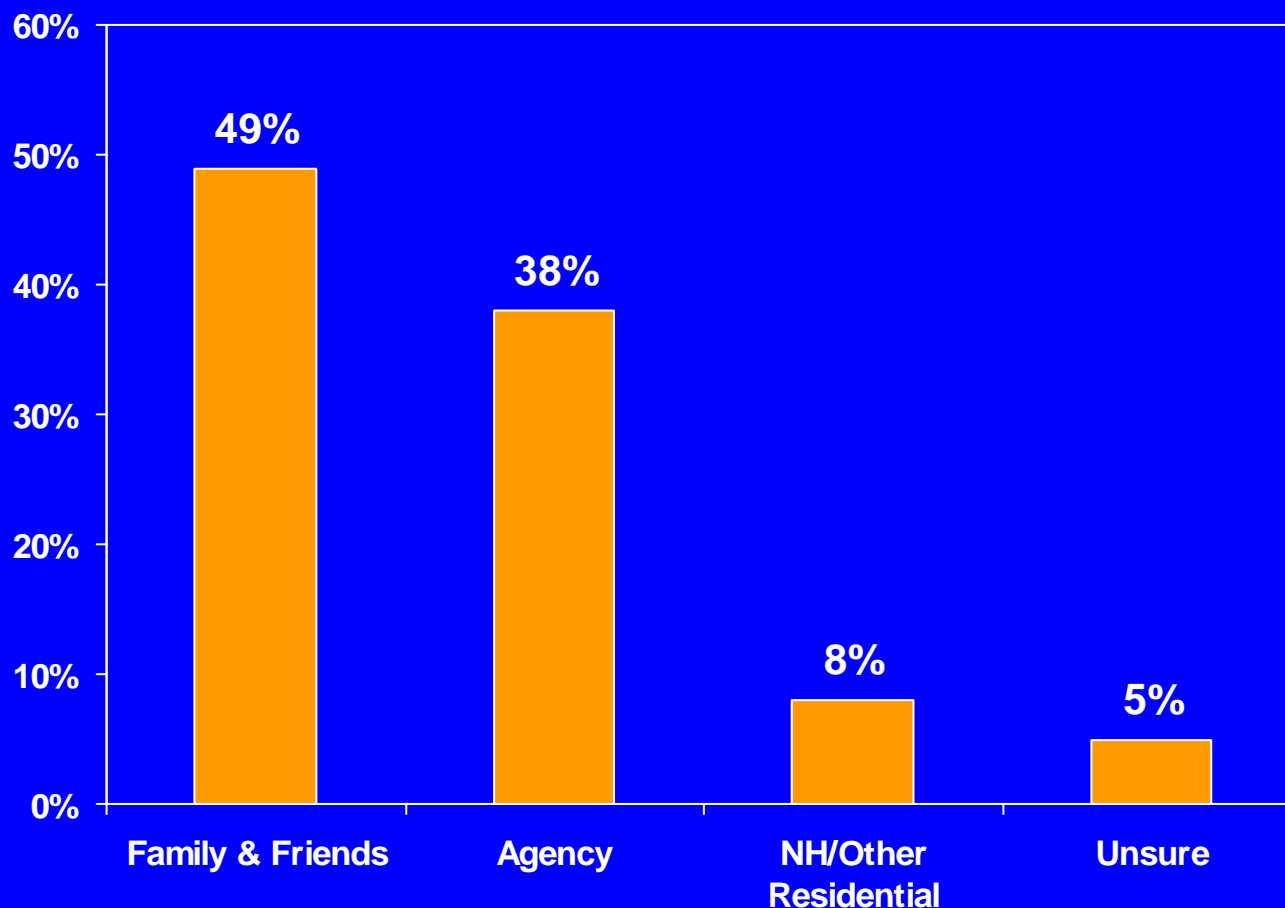
How Many Family Caregivers?

- Identified by who?
- Parameters on Help:
 - Kinds of help (what types of tasks?)
 - Time horizon/frequency/hours of care
 - Identity of caregiver (relation, payment)
- Primary versus secondary

Why are we talking
about family caregiving?

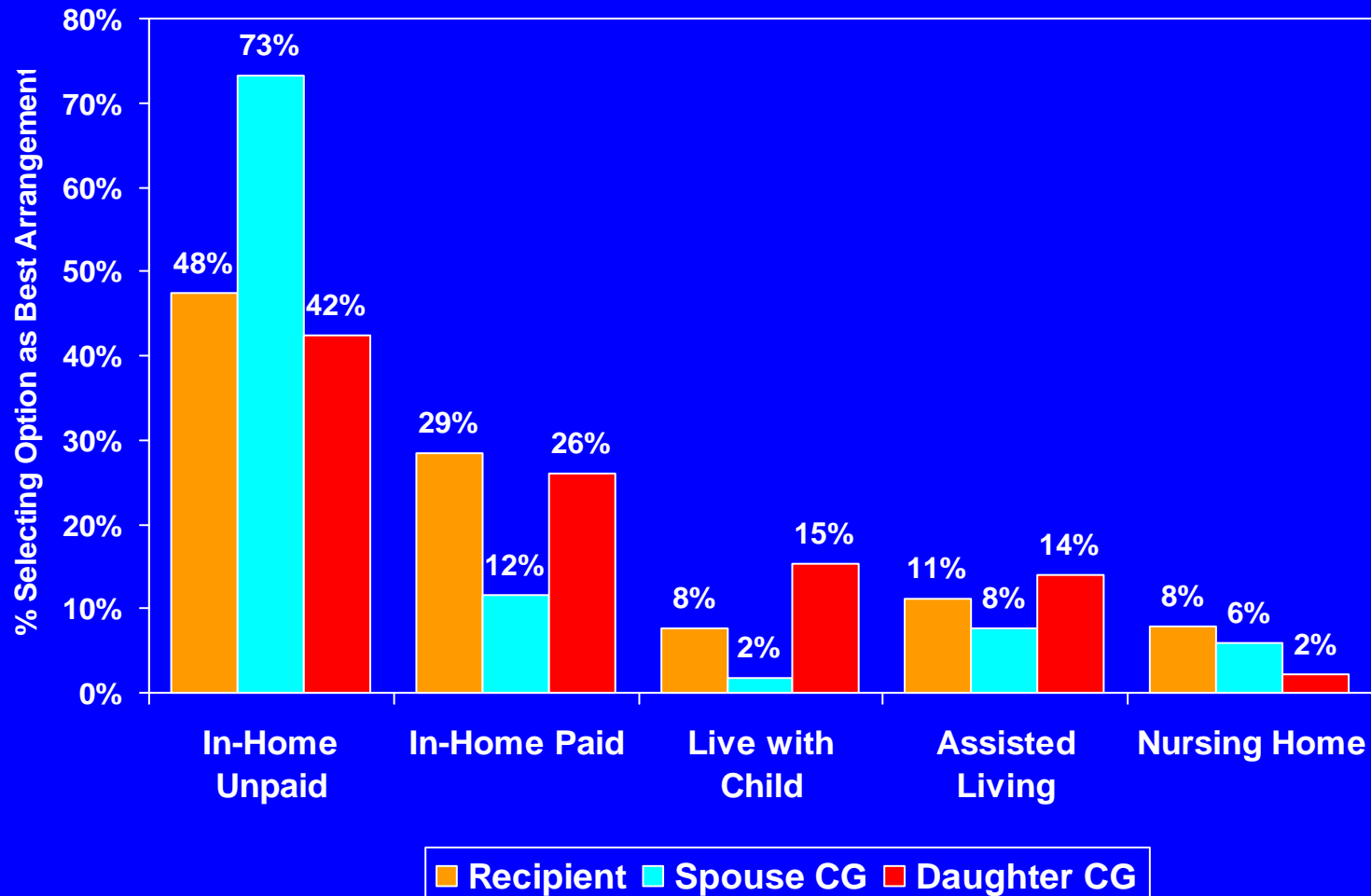
1st Choice of Long-Term Provider

n=1,243 Community-Dwelling Individuals Receiving Help,
Ages 50+



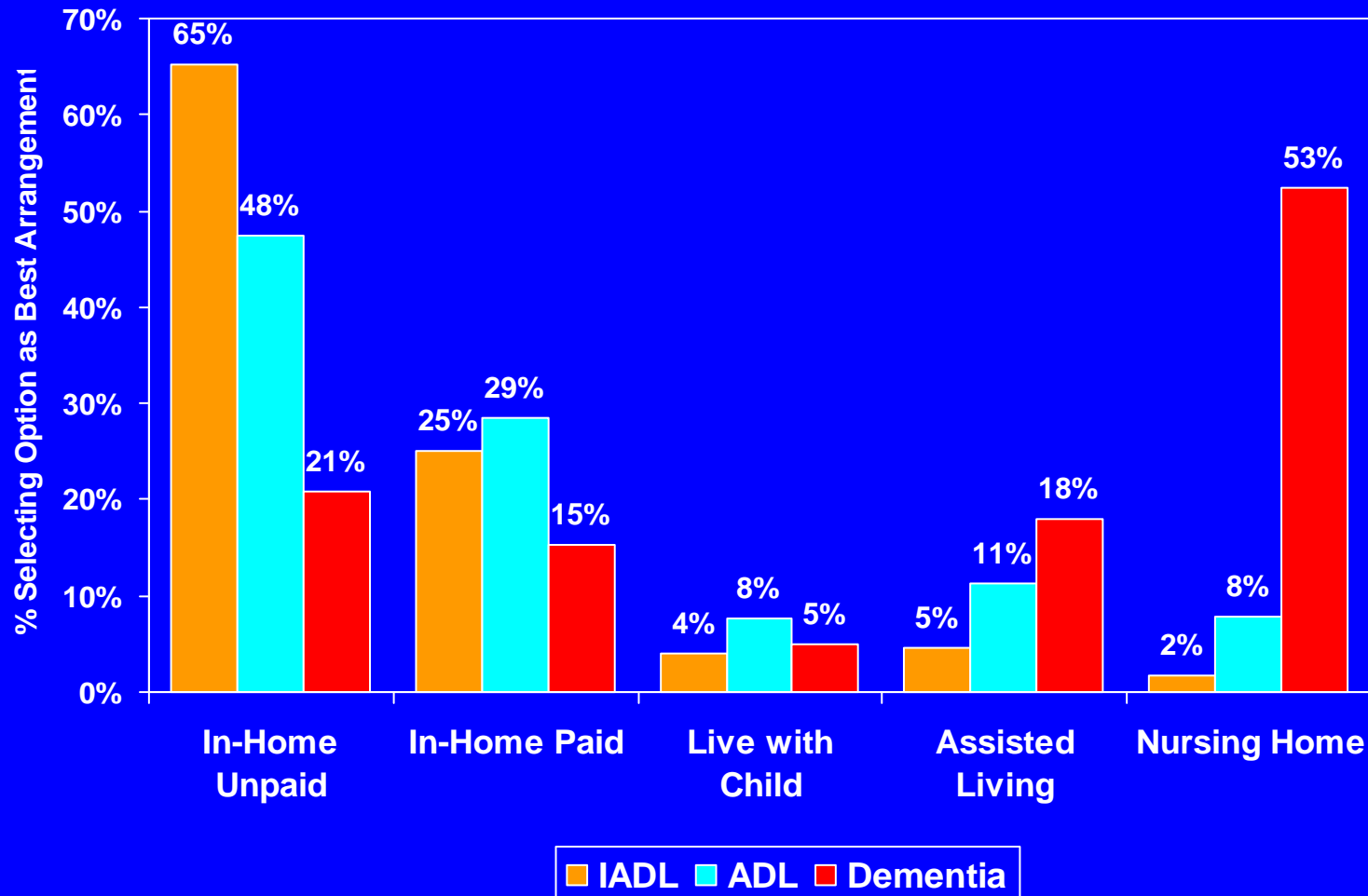
Source: Kassner E, Bectel RW., Mid-life and older Americans with disabilities: who gets help? A chartbook. Washington, DC: Public Policy Institute, American Association of Retired Persons; 1998.

Caregiver Preferences: A Moving Target? Scenario of ADL Needs, WHAS Data



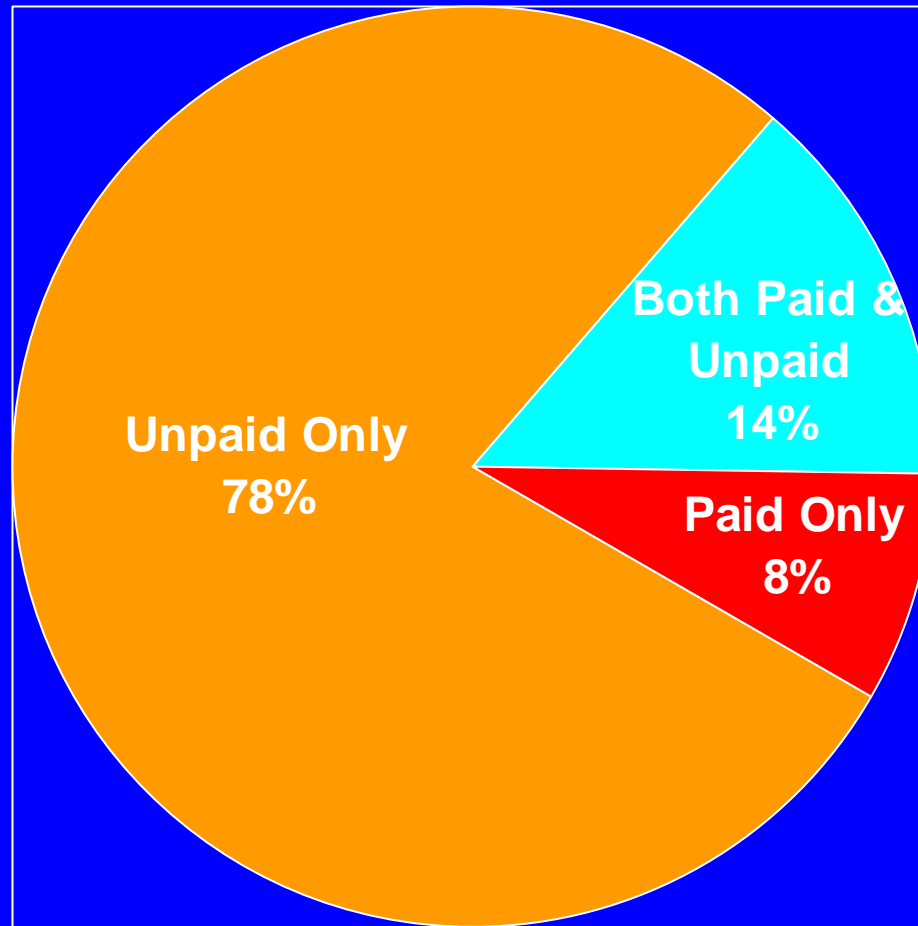
Source: Kasper et al., Aging Clin Exp Res 2000

Care Recipients' Preferences: A Moving Target? Scenarios of IADL, ADL, Dementia

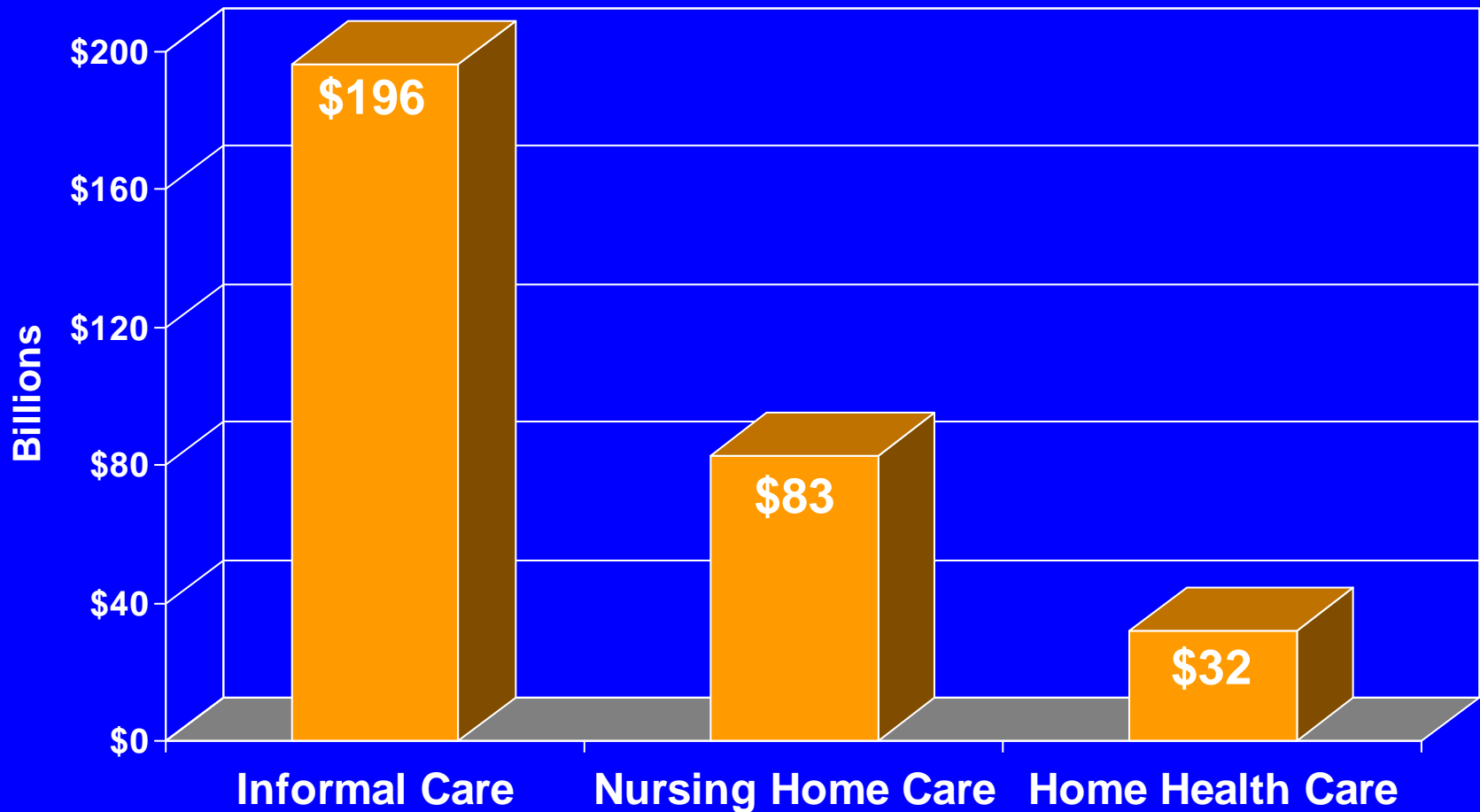


Source: Kasper et. al., Aging Clin. Exp. Res., 2000

Adults Receiving Help at Home: Type of Care



Economic Value by Type of Long-Term Care Assistance, 1997

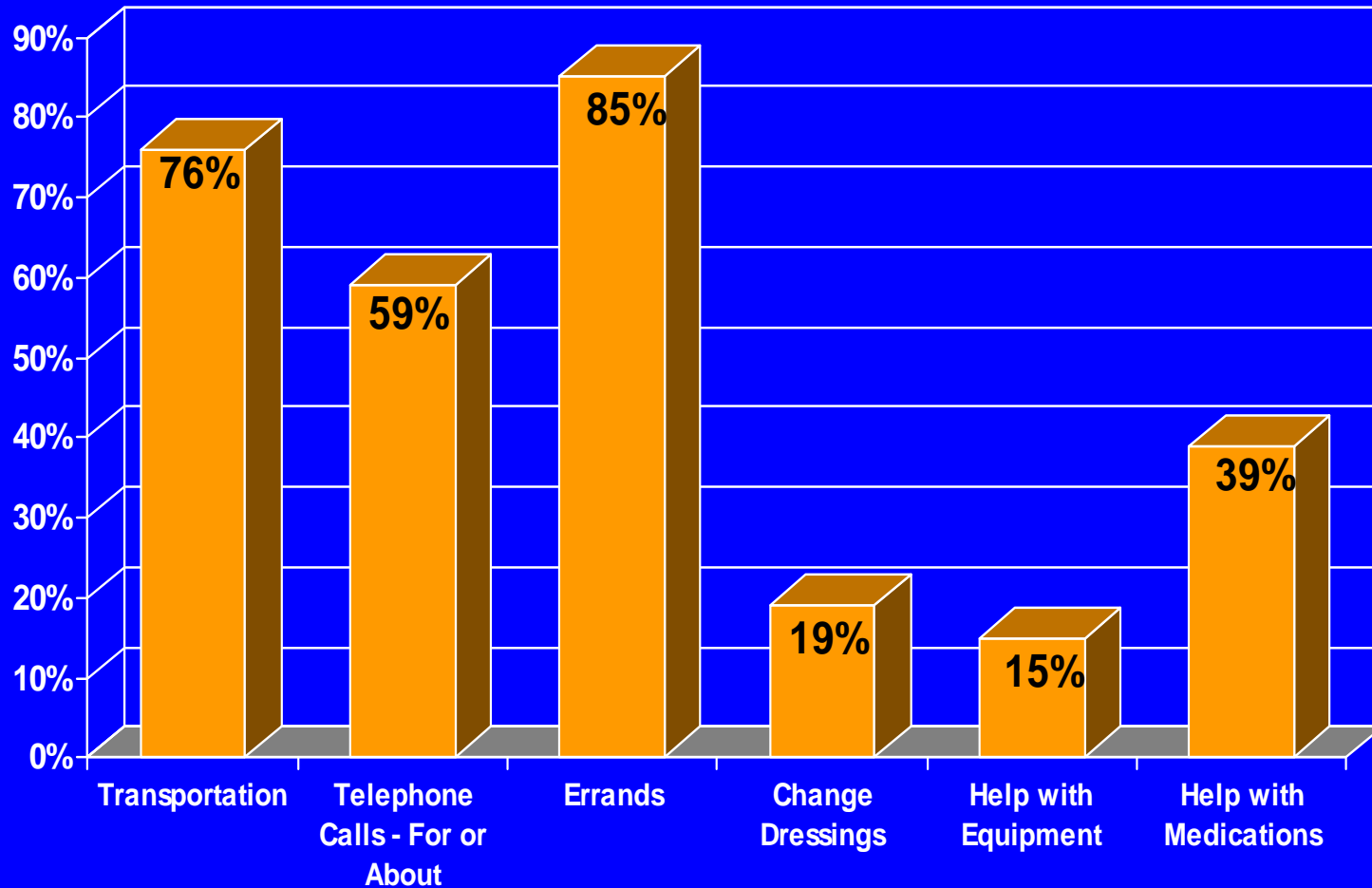


Source: Arno, Levine, and Memmott. Health Affairs, 1999

Informal Care Costs of Dementia: 1986-1998

Study	Sample Size ^a	Caregiving Hours/Week	Hourly Wage	Annual Per Capita Costs ^b	Components of Costs of Care
Hu et al. 1986 Huang et al. 1988	19 in Pennsylvania and Washington DC	44.1	\$4.26 (nurse aide)	\$25,910	ADL, taking medicine, supervision
Rice et al. 1993 Max et al. 1995	93 in northern California	66.5	\$10.40 (nurse aide) \$8.41 (housekeeper) \$12.12 (bookkeeper) \$11.37 (maintenance)	\$57,937	ADL/IADL, behavioral management, social/recreational activities
Weinberger et al. 1993	264 in North Carolina	70	\$10	\$56,036	Respite care, chores, meal preparation
Ernst and Hay 1994	Published data from various sources	52.5	\$10.30 (10% higher than home health aide wage)	\$38,086	NA
Stommel et al. 1994	182 in Michigan	35.7	\$7.82 (home health aide) \$6.00 (homemaker)	\$20,813	Personal care, housework, supervision
Arno et al. 1997	From 1986 SIPP and 1996 NSFH	18.2	Average of \$11.20 (home health aide) and \$5.15 (minimum wage)	Total cost \$209 billion	NA
Ostbye and Crosse 1997	9,008 from Canadian Study of Health and Aging	11.2–20.3	\$CND10	\$CND5,130	ADL/IADL
Leon et al. 1998	679 from 9 states	NA	\$6.95 (hh aide) \$6.08 (housekeeper)	\$12,730	ADL/IADL

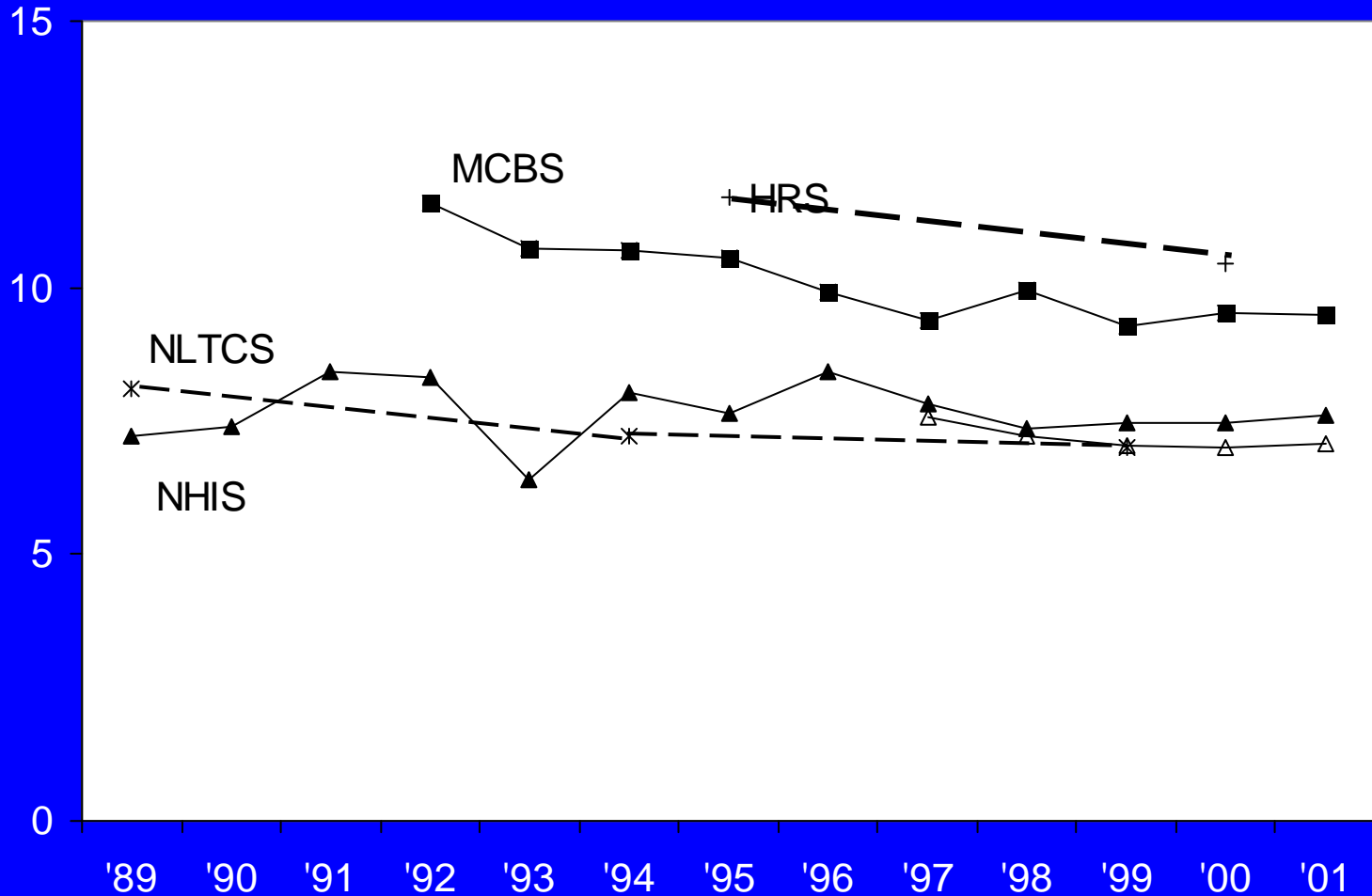
Beyond Personal Care



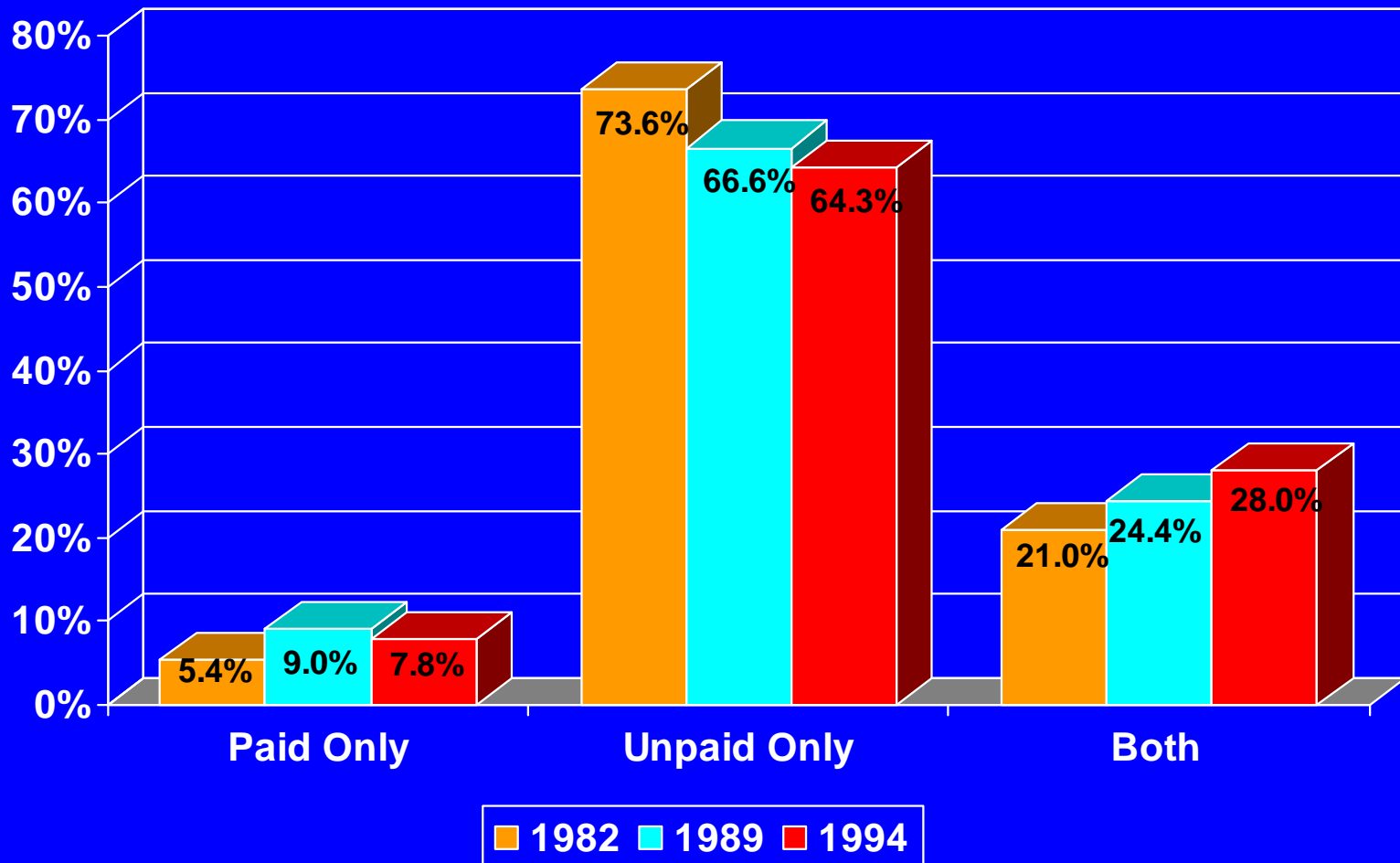
Source: Donelan, et al. Health Affairs, 2002

Trends in Family Caregiving

Percentage of the community-based population ages 70 and older reporting *getting help* with one or more of 6 activities of daily living



Sources of Assistance: 1982-1994 National Long Term Care Survey

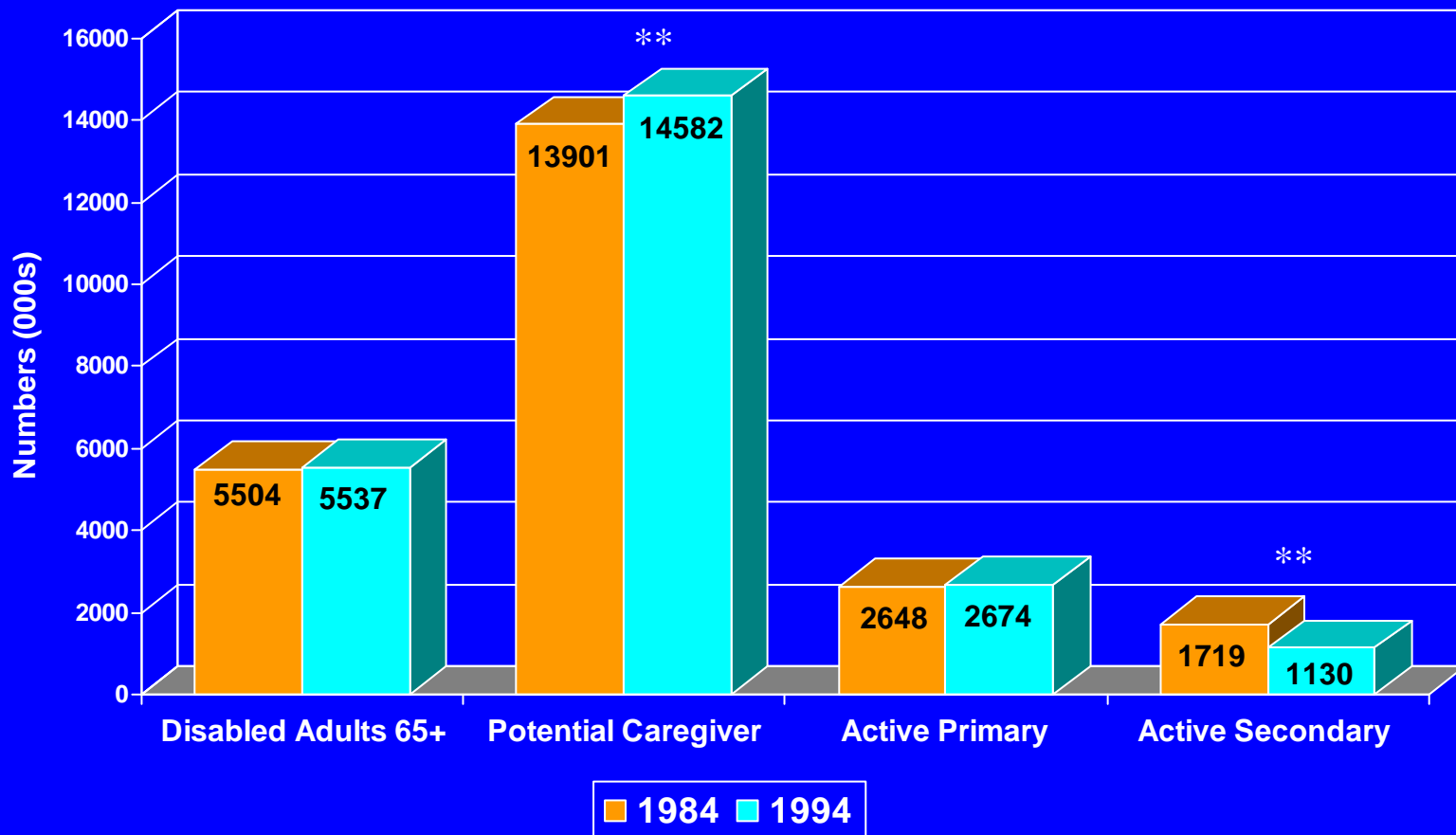


Source: Liu et al., J Gerontol Soc Sci, 2000

Potential & Active Family Caregivers, NLTCS

% of US Population

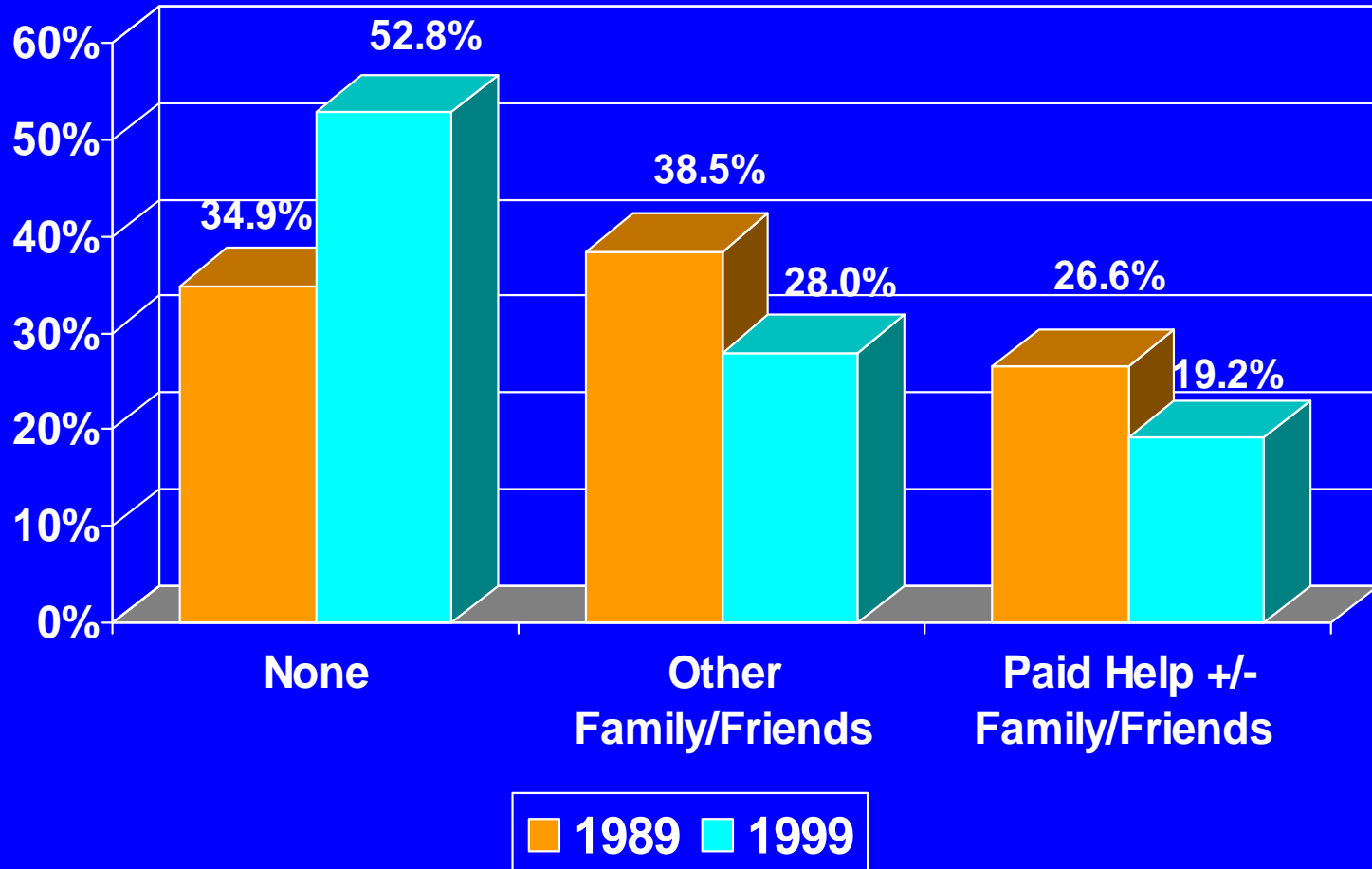
7.5 7.2 1.4 1.3 0.9 0.5



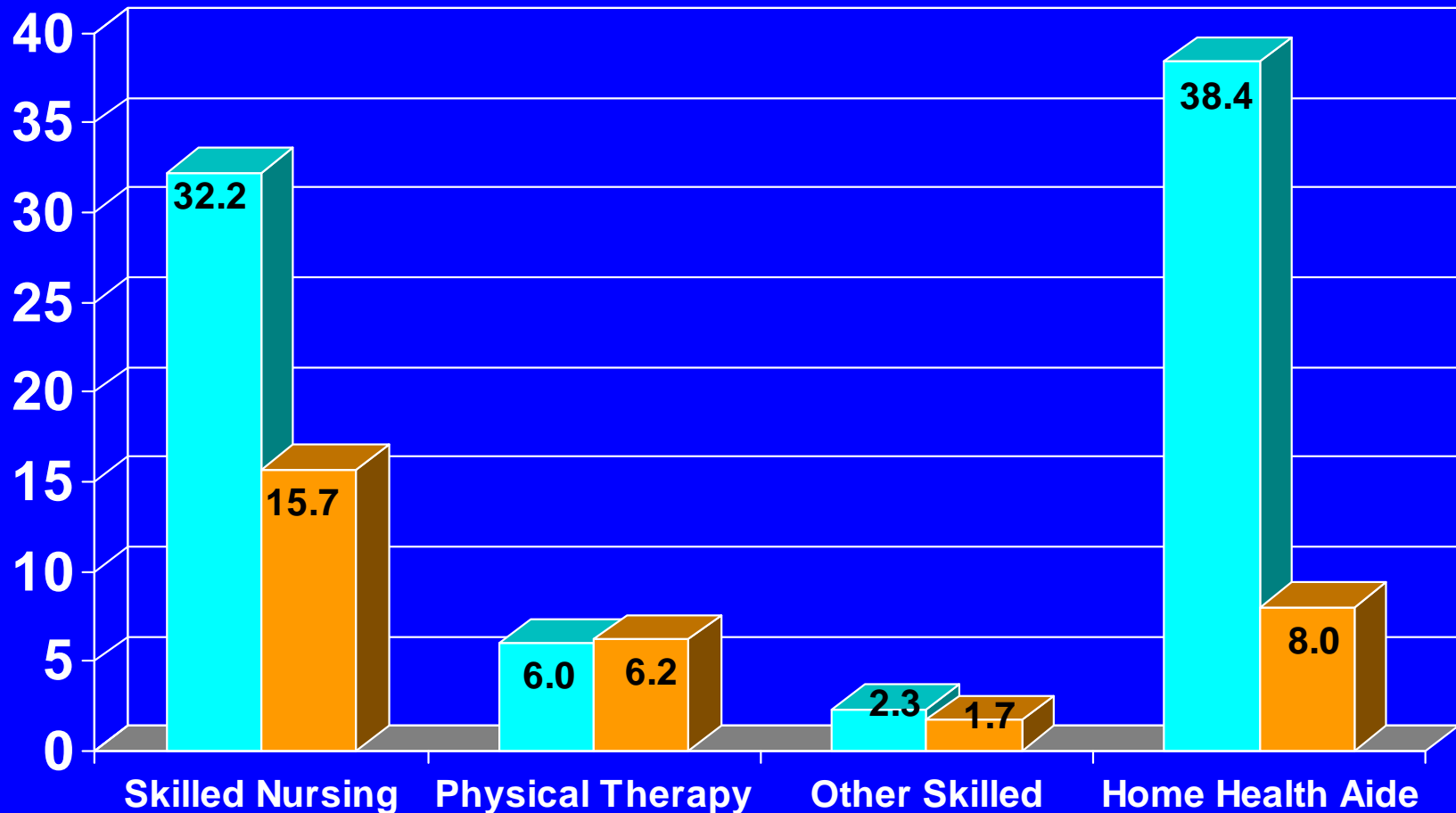
Source: Spillman & Pezzin, Milbank Q, 2000.

**p<0.05; * p<0.10

Secondary Caregiver Involvement Has Declined



Mean Number of Medicare Home Health Visits Per User, 1997 & 2001

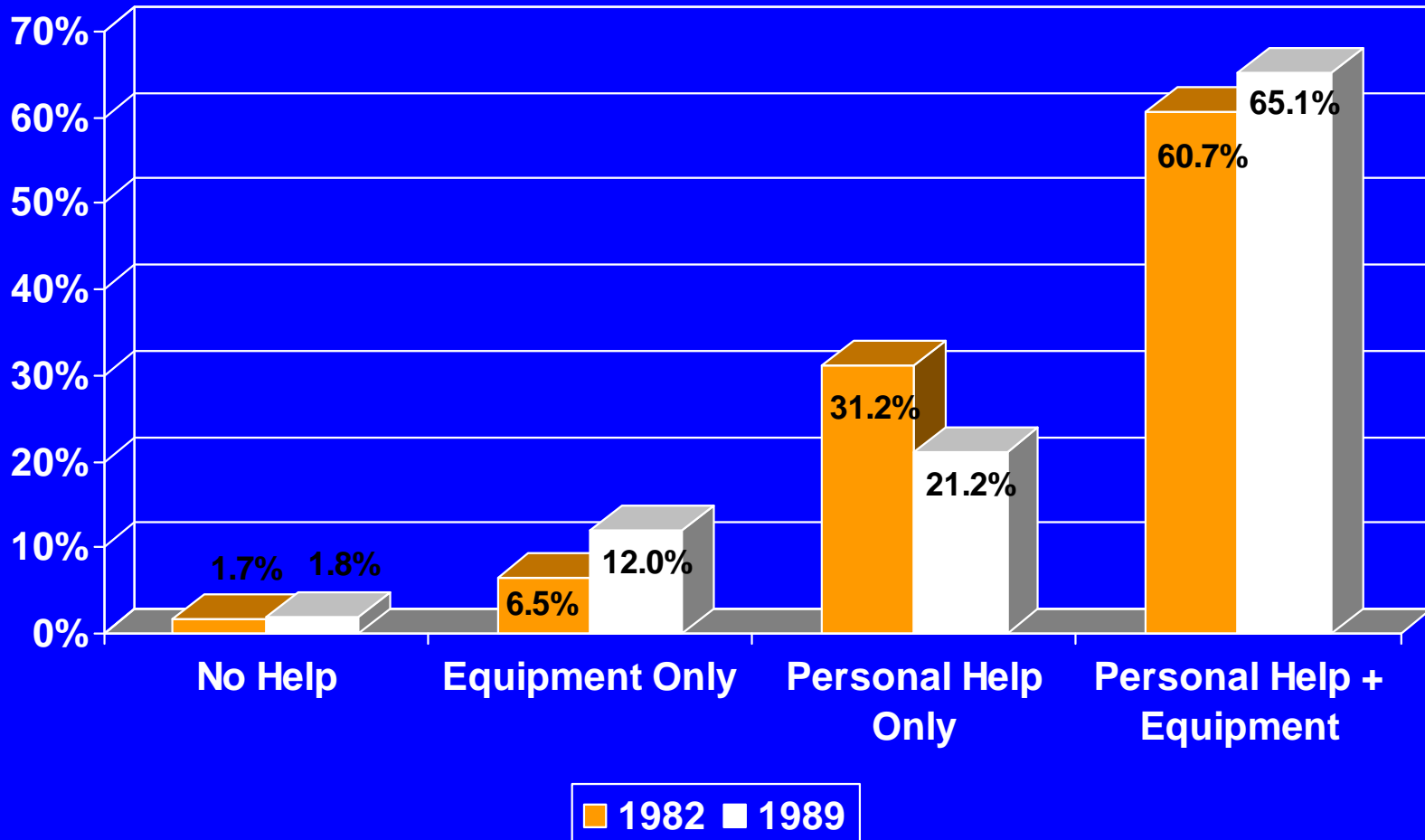


Source: Murtaugh CM, et al. Health Affairs, 2003

■ 1997 ■ 2001

Does AT Offset Personal Care?

Method of Compensation Among Chronically Disabled Adults Ages 65+



Source: Manton et al. Gerontologist, 1993

Key Issues in Family Caregiving

- Longer life expectancy & delayed fertility
- Declines in disability?
- Sandwich generation issues
 - Dual income families
 - Declines in numbers of secondary caregivers
- Geographic mobility
- Medicaid policy & growing support for deinstitutionalization
- Medicare prospective payments, e.g. home health

Unpaid. Unappreciated. Untrained.
Undercounted. Exhausted. But vital.

“America’s stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And, to tell you the truth, sometimes she doesn’t feel that great herself...”

-- AMA Medical News, 2001

Family Care Consequences: Evidence from the Literature

- Recipient Benefits

- Lower risk of permanent nursing home entry, hospitalization (e.g. Miller & Weissert, *Med Care Res Rev.* Sep 2000;57(3):259-297)
- Lower likelihood of “unmet need”

- Caregiver Costs

- Physical, economic, social, emotional burden associated with providing care
- Financial costs
- Mortality (?)

Does High Caregiver Stress Lead to Nursing Home Entry? (Spillman & Long, 2007)

<u>SIGNIFICANT DIFFERENCES</u>	Stress on 10 point scale	
	Less than 6	6 +
Female Gender	65%	74%
Fair/Poor Health	26%	50%
Health Worse Since Began CG	6%	43%
Provide 20+ Hours / Week	43%	73%
Physical Strain (3+ on 5-point scale)	21%	76%
Problem Behaviors 3+ Times/ Week	12%	42%
<u>NOT SIGNIFICANT:</u> Age, CR/CG Relationship, Competing Child Care Demands, Serving as Sole Caregiver, Duration of Providing Care		

Source: Spillman & Long, ASPE Report, January 2007

Does High Caregiver Stress Lead to Nursing Home Entry? (Spillman & Long, 2007)

Nursing Home Entry (MDS nursing home stay of >60 days) was rare!

4% of care recipients experienced nursing home stay >60 days within 6 months of interview; 7% in 12 months, and 13% within 24 months

Recipients with highly stressed primary caregiver 17% more likely to experience nursing home stay in 24 months of interview

Caregiving and Mortality

Variables	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Sociodemographic factors		
Age	1.11 (10.7-1.15) ^a	1.10 (1.06-1.14) ^a
Sex	2.39 (1.58-3.62) ^a	1.88 (1.23-2.88) ^b
Race	1.14 (0.61-2.13)	2.00 (1.03-3.89) ^c
Education, y	0.99 (0.95-1.03)	1.00 (0.96-1.05)
Stressful life events	0.93 (0.75-1.15)	0.83 (0.67-1.03)
Baseline physical health status		
Prevalent disease ^d	4.55 (2.52-8.24) ^a	3.30 (1.79-6.08) ^a
Subclinical disease (no prevalent disease)	2.21 (1.20-4.08) ^c	1.84 (0.99-3.42)
Baseline caregiving status^e		
Not helping disabled spouse	1.84 (0.99-3.45)	1.37 (0.73-2.58)
Helping disabled spouse (no caregiving strain)	1.40 (0.81-2.42)	1.08 (0.61-1.90)
Helping disabled spouse (caregiving strain)	1.75 (1.10-2.80) ^c	1.63 (1.00-2.65) ^c

^a $P < 0.001$; ^b $P < 0.01$; ^c $P < 0.05$; ^dReference category is no subclinical or prevalent disease;

^eReference category is no spouse disability. Source: Schulz & Beach, JAMA, 1999

Types of Interventions

- Objective Burden → Reduce Intensity of Care or Amount of Care
 - Respite Care/Adult Day Care
 - Training Care Recipient
- Subjective Burden → Target Well-Being and Coping Abilities
 - Psychoeducational Interventions
 - Psychotherapy
 - Support Groups
- Multicomponent Interventions – Some Combination of the Above

Types of Outcomes: A Sampling

- Caregiver Burden
 - Zarit, Montgomery, Borgatta Burden Scale; Schulz Caregiver Strain
- Caregiver Depression
 - CESD, GDS, Beck Depression Inventory...
- Caregiver Well-Being
 - Life Satisfaction, Affect Balance Scale, others...
- Caregiver's Ability/Knowledge
- Care Recipient's Symptoms

Do Caregiver Interventions Work?

Caregiver Burden

	# Effects	# Participants	Mean Effect Size
Psychoeducation	33	1,215	-.12 **
Support	5	134	-.35 **
Psychotherapy	11	305	-.31 ***
Respite	11	682	-.30 ***
Training Recipient	6	110	-.08
Multicomponent	7	446	-.62 ***

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

Source: Sorensen et al. Gerontologist, 2002

Caregiver Support: National Family Caregiver Support Program

- Older Americans Act of 2000
- \$158 million in 2007
- Obtaining services
- Counseling
- Training of counselors
- Respite care
- Supplemental services

How Should Society Support Family Caregivers?

Types of Supportive Services	% Using Service	Fully Met Needs (%)
Obtained assistive device	50.4	79.2
Personal/nursing care	34.7	70.3
Home modification	22.0	78.4
Housework service	15.5	72.3
Home delivered meals	12.4	60.3
Financial information	11.8	21.4
Transportation	11.5	71.8
Respite care	7.6	80.8
Support group	5.0	59.0
Adult day care	4.7	46.9

Source: 1999 National Long Term Care Survey and Informal Caregivers Survey

Caregiving: Emerging Areas

- Dyadic research
- Health care outcomes other than institutionalization (e.g. quality of care)
- Interface between caregivers and medical system
- Caregiving preferences
- Longitudinality: trajectories of caregiving, trends in caregiving
- Caregiving relationships: positive and negative dimensions
- Caregiving at a distance; telehealth