

The Hilltop Institute Symposium  
Home and Community-Based Services:  
*Examining the Evidence Base for State Policymakers*  
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# The Caregiving Continuum: Costs & Benefits Reconsidered

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## American Mosaic

Edith Arno

87-year-old Arno has seen a lot of change in her lifetime. But she can't find another period of American history that feels similar. "This is the first time in my lifetime that they really crossed lines," says Arno, a native of Brooklyn who has lived in New York City her whole life. "It shows that people are more educated, more open to listening and thinking for themselves." Arno is confident that her 18-month-old great-grandson is growing up in a better country with more opportunities.



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“Research on healthy aging as well as aging-related diseases is essential. At the same time, we need to understand the **socioeconomic**, moral, cultural, and personal consequences of the new longevity and population aging.”

*Butler, 2001*

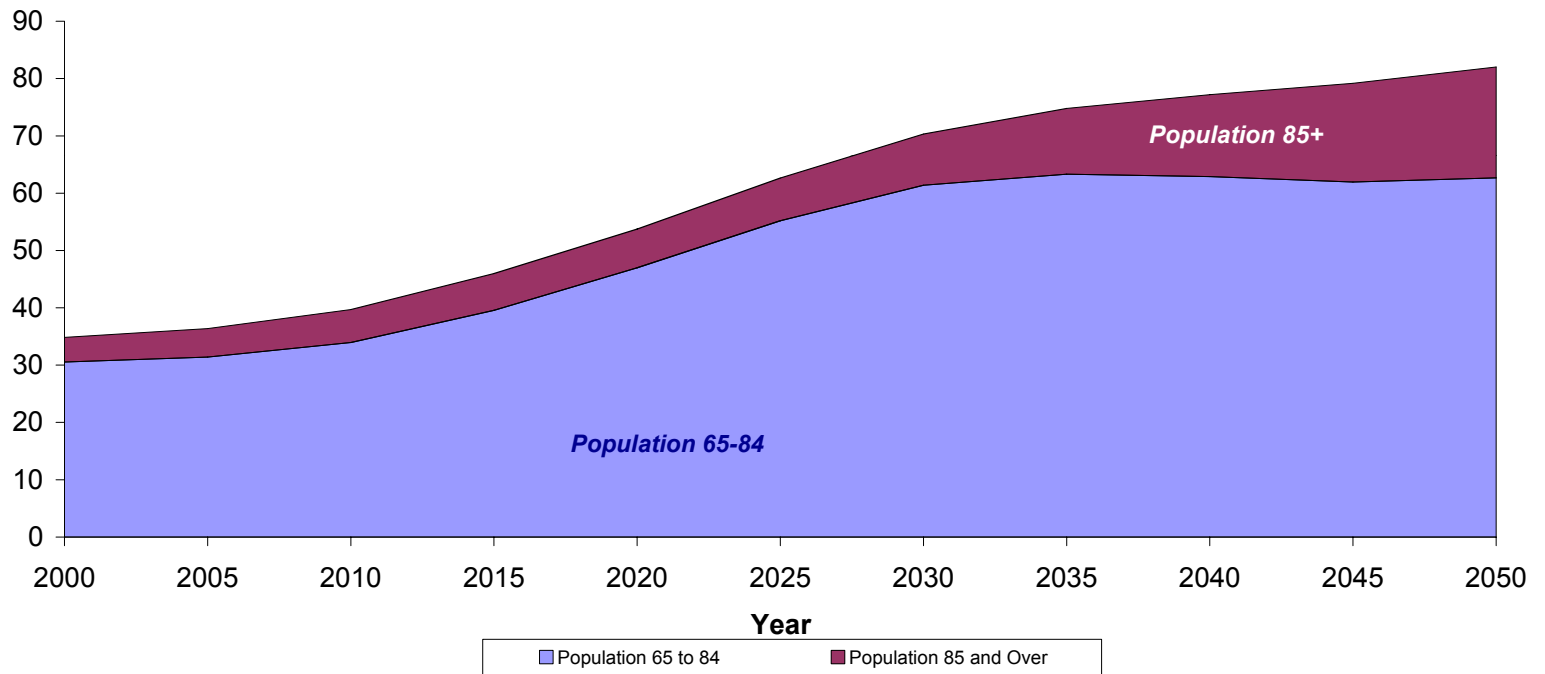


# Socioeconomic Consequences affect Caregivers and Care Recipients

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- Income
- Education
- Race/Ethnicity
- Gender
- Age
- Marital Status
- Socialization

# Population Projections 65 to 84 and 85 and over, 2000 to 2050



U.S. Dept. of Commerce, Bureau of the Census, 2004



## More care needed

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- Growth in older groups 70-84 and 85+ will have chronic conditions requiring care
- Living arrangements:  
2/3 of women 75+ live alone vs.  
<1/3 of men the same age
- Decreasing fertility rates means fewer family members are available to provide caregiving

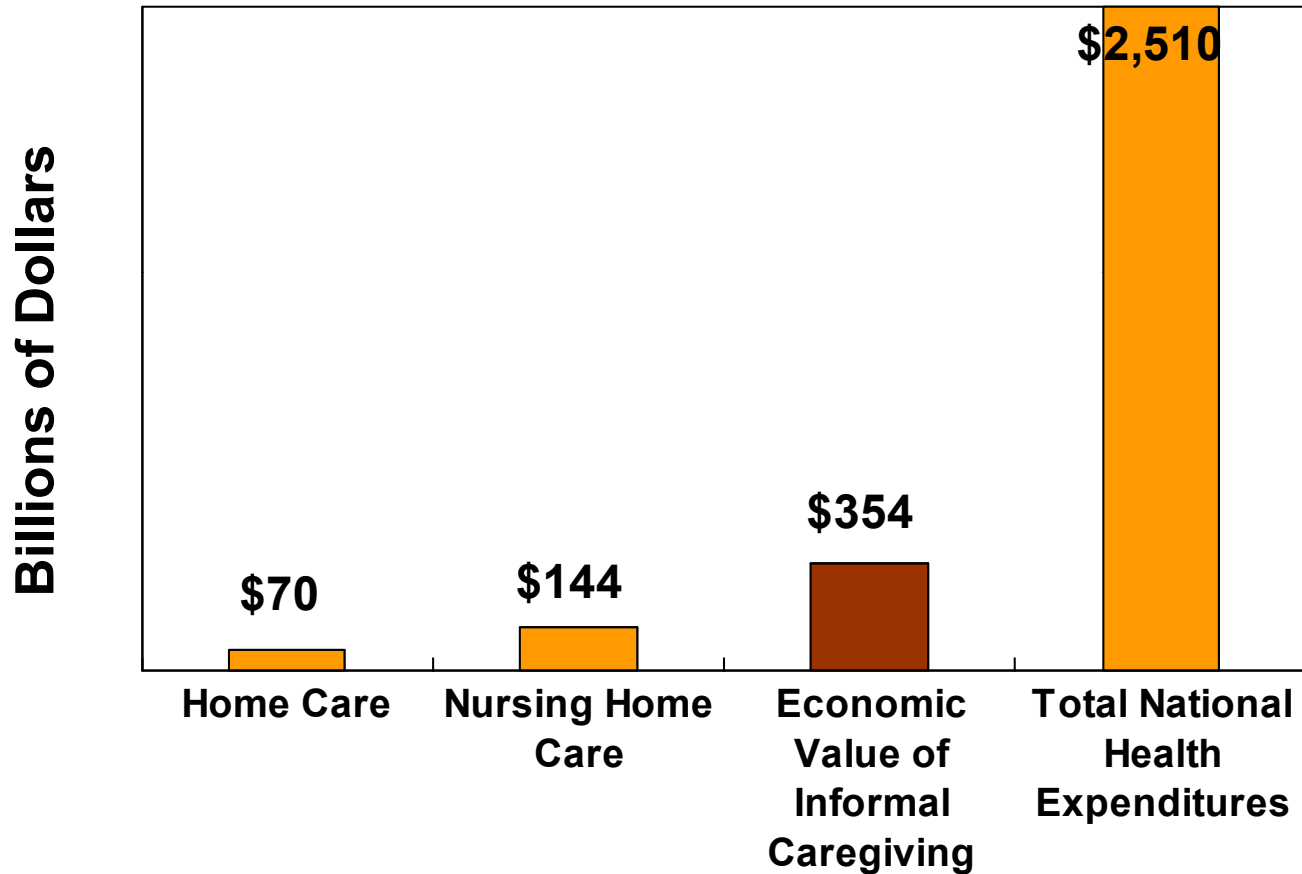
# Assistance Received by Care Recipients

Activity	Employed Caregivers (%)				Nonemployed Caregivers (%)			
	Care Recipients Needing Help (%)	Source of Help <sup>a</sup>			Care Recipients Needing Help (%)	Source of Help <sup>a</sup>		
		Caregiver	Family/ Friends/ Neighbors	Paid Provider		Caregiver	Family/ Friends/ Neighbors	Paid Provider
Transportation/shopping	83	84	44***	12	86	85	32	12
Household chores	71	70	43***	28	75	74	28	25
Managing finances	64	72	44***	3	65	79*	31	5
Arranging for care	53	80	45***	6	55	83	30	9
Medical needs	45	69	40***	29	52*	76	26	23
Personal care	38	64	39	40**	43	72	32	29

Notes: <sup>a</sup>Computed as a percentage of the number of care recipients needing each type of help.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

# Estimated Home Care, Nursing Home Care, Informal Caregiving and National Health Expenditures, U.S. 2009

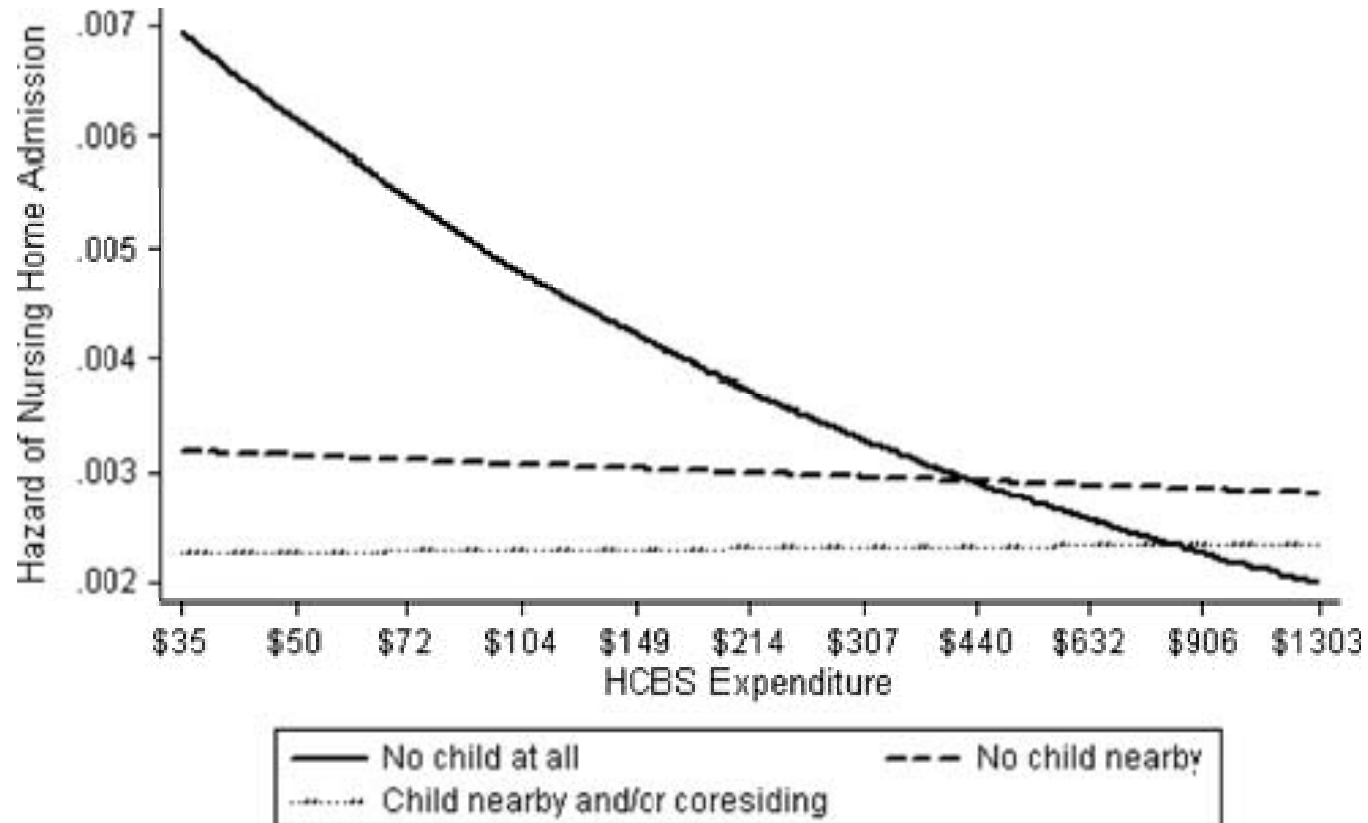


Expenditure data from Office of the Actuary, CMS, Health Affairs, 2009

Informal caregiving estimates based on authors' estimates



# HCBS and Nursing Home Tradeoff



Muramatsu et al, 2007



# Economic Advantages

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Imputing an economic value to the extraordinary level of caregiving described in this study does not detract from the emotional, cultural, and societal values expressed through informal caregiving. On the contrary, it enhances their importance by providing a tangible measure of the vast but vulnerable base upon which our chronic care system rests.

Arno et al, 1999



# Need for More Affordable Care

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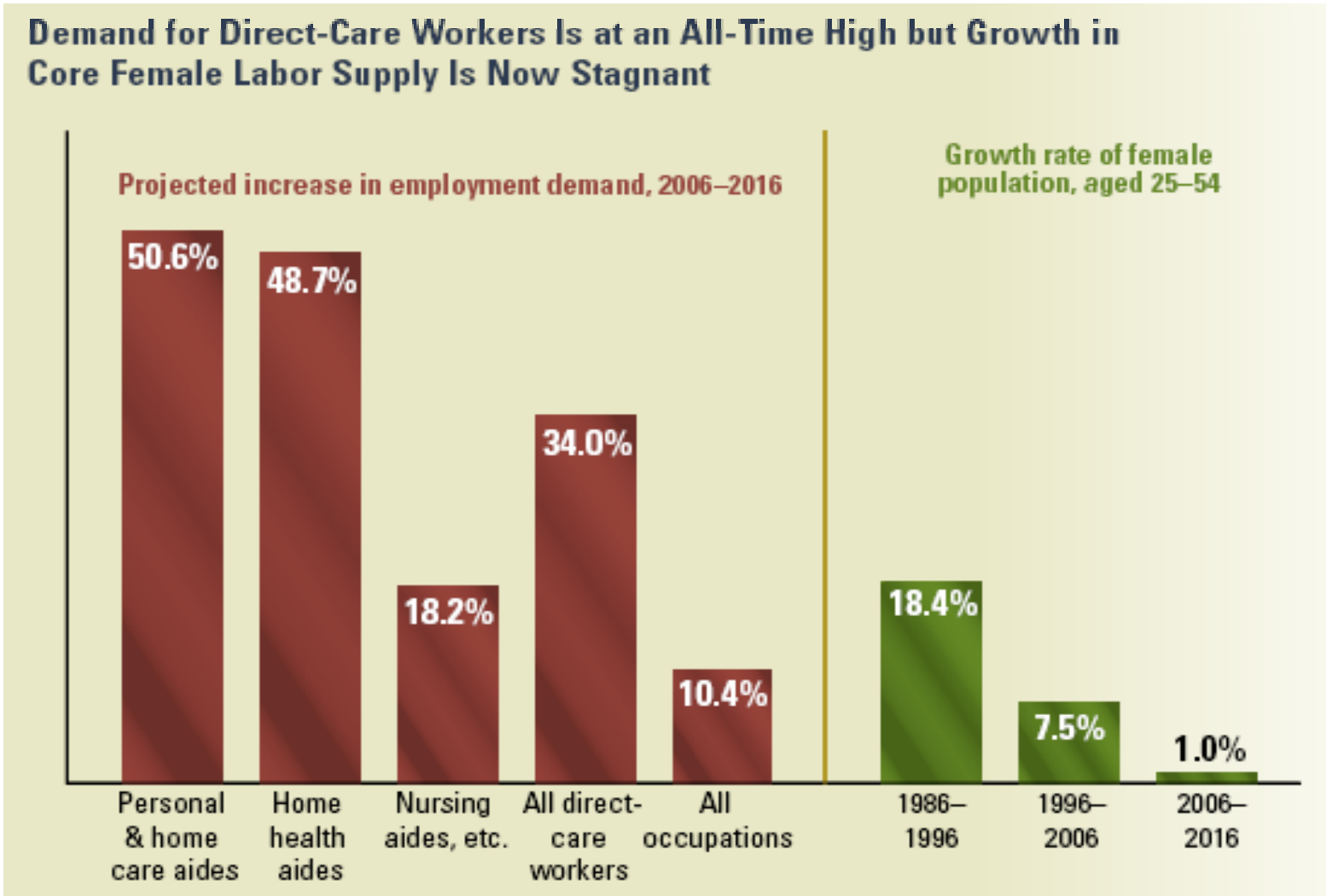
- The majority of elderly people lifted from poverty by Social Security are women.
  - About two-thirds of elderly women who otherwise would be poor -- 66% -- are removed from poverty by Social Security.
- However, about 20% of elderly who require assistance are not able to obtain any type of care.



# A Better Care Economy

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- Labor force participation rates for women have leveled off.
- Growth in household incomes has also leveled off as a result.
  - The economic costs of caring for family members are rising.
  - Caregiver options are fewer as labor supply for formal caregivers has not kept up.



PHI (April 2008) *Occupational Projections for Direct-Care Workers 2006-2016*, PHI Facts 1, Bronx, NY: PHI.



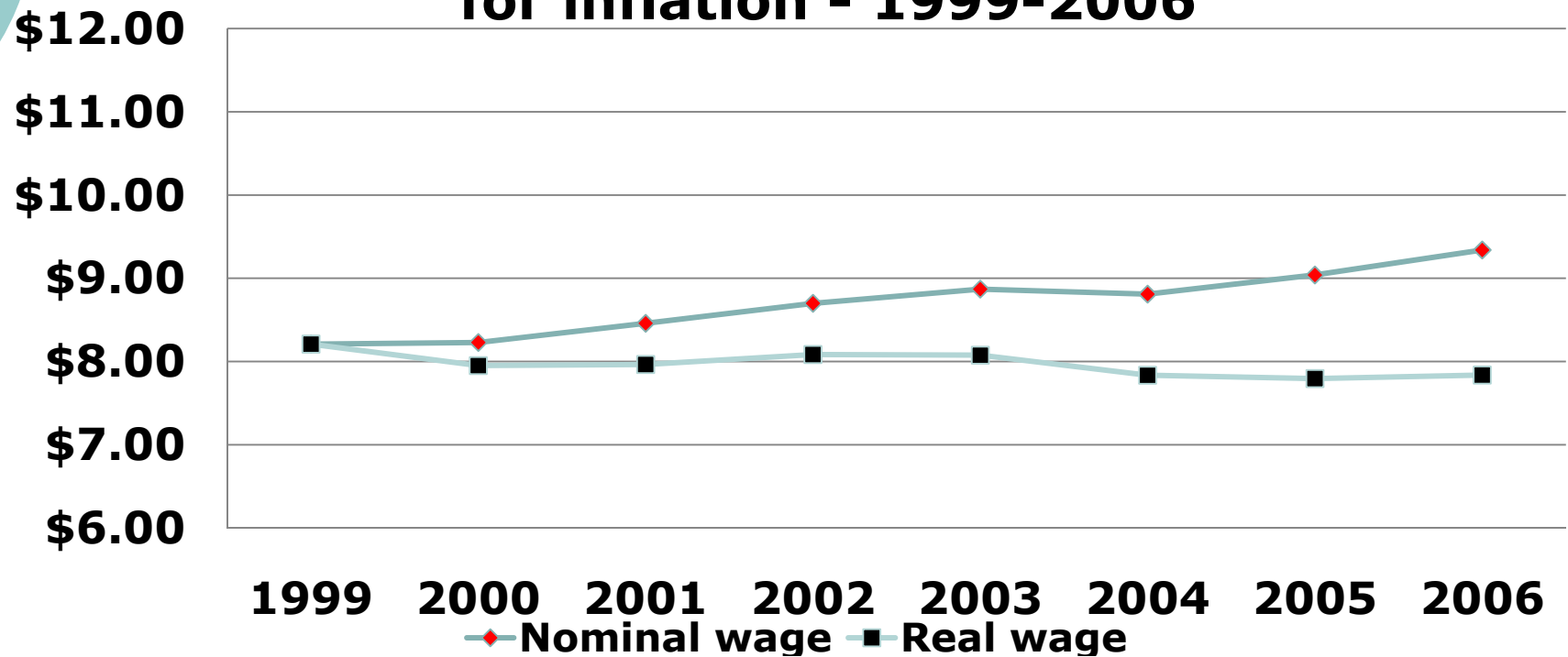
# A Better Care Economy

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- Policy initiatives must be threefold:
  - Make caregiving professions an attractive career choice;
  - Compensate direct and indirect costs of informal caregivers;
  - Consider the continuum of care as a mix of informal, formal and long-term care.
- Today's presentations should "motivate the need to develop a more complete vision of a generous, equitable, efficient, and sustainable care economy."

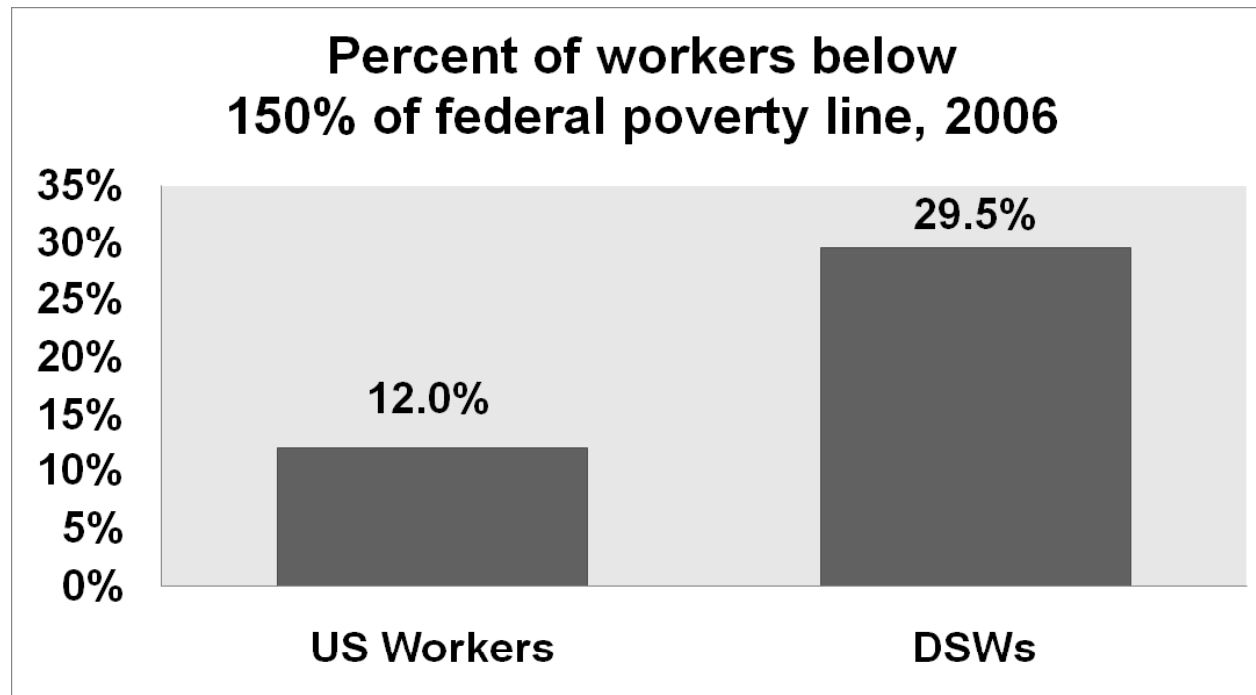
# Home Health Aides: Trends in Real Wages

**Median hourly wage, nominal & adjusted for inflation - 1999-2006**



Source: PHI analysis of CPS 2007

# Home Health Aides Disproportionately Live in or near Poverty, w/o Benefits



Uninsured

18%

29.2%

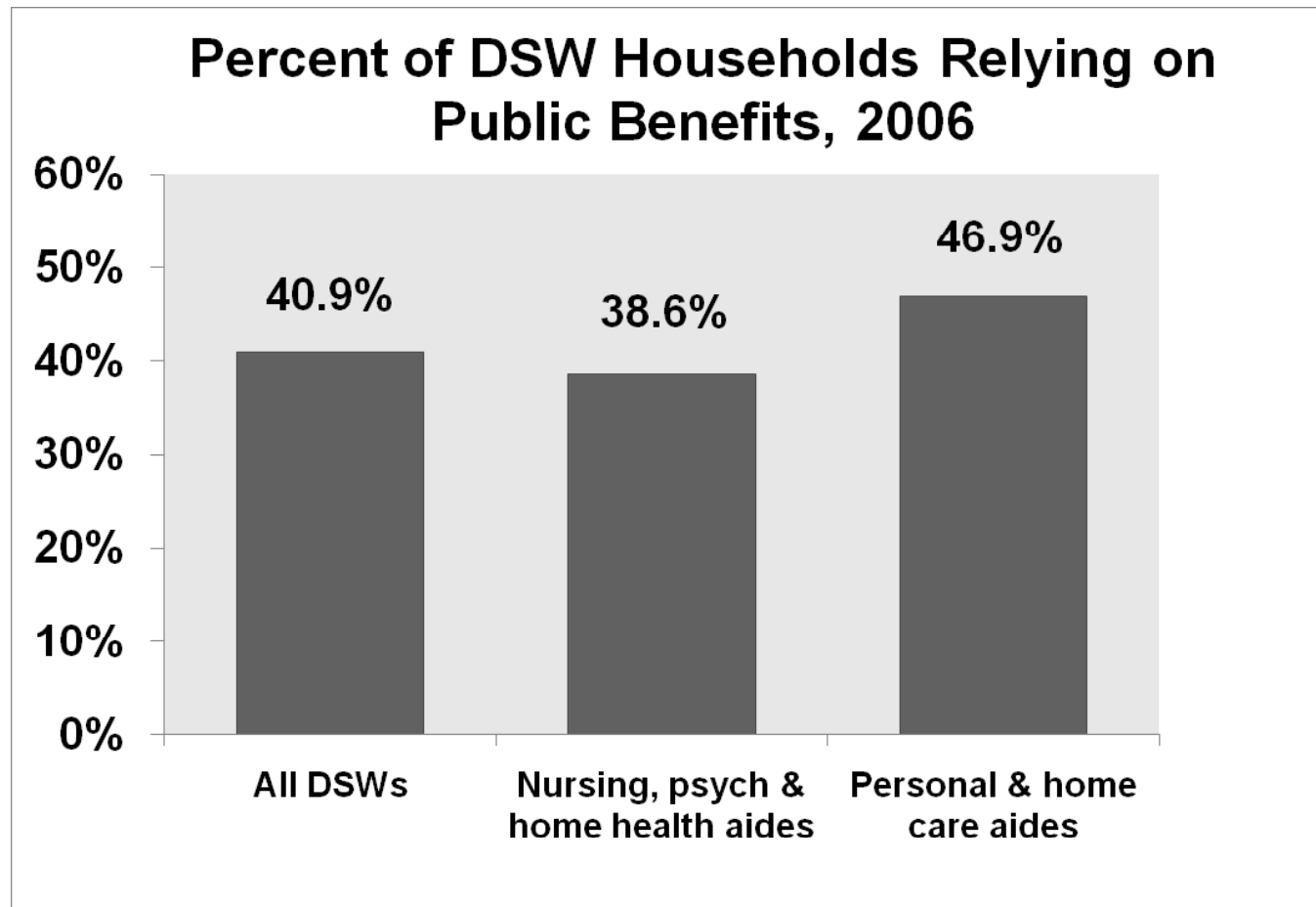
Median income

\$32,140

\$16,000



# Dependence of Home Health Aides on Public Benefits



Source: PHI analysis of CPS 2007



# Make Career more Attractive

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## **IOM Recommendation 5.2**

“State Medicaid programs should increase pay and fringe benefits for direct-care workers through such measures as wage pass-throughs, setting wage floors, establishing minimum percentages of service rates directed to direct-care labor costs, and other means.”



# Subject Areas Covered in Home Health Aide Competency Tests

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- Communication skills
- Observation, reporting, and documentation of patient status and the care or services furnished
- Reading and recording vital signs
- Basic infection-control procedures
- Basic elements of body function and changes
- Maintenance of a clean, safe, and healthy environment
- Recognition of, and procedures for, emergencies
- The physical, emotional, and developmental characteristics of the patients served
- Personal hygiene and grooming
- Safe transfer techniques
- Normal range of motion and positioning
- Basic nutrition

SOURCE: *Home Health Aide Training*. 2006. 42 C.F.R. § 484.36.



## In addition to Wage & Benefits, Support Career Ladders

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- Provide ongoing training and continuing education to motivate quality care, including ESL workshops.
- Allow for tuition support for certification as nurse aide; nurse; other clinical therapy occupations.



## Compensating Informal Caregivers

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- To date, no U.S. federal tax-based relief for caregivers' time exists
  - Direct costs are allowed as deductions under Dependent Care Tax Credit, but limited.
  - States' approaches vary considerably.
    - Only seven states provide a tax credit for caregivers' time, but credits are limited.



# Caregivers' Use of Credit

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- In one survey in Hawaii, “caregivers say they would use a portion of a tax credit to purchase professional care for their elderly relatives.”
  - This result was true for both employed and non-employed family caregivers.
  - This result may obviate the concern that tax credits would incent a substitution away from formal caregiving or long term care.

Nixon, 2007



## Additional Costs of Informal Caregiving

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- Numerous studies have found that stress, time spent with family/friends, amount of medication use, lost time at work and misuse of alcohol or prescription drugs, incidence of coronary heart disease, and depression are negatively associated with caregiving.

*Caregiving and Risk of Coronary Heart Disease in U.S. Women. Lee et al. Amer J of Prev Med 2003;24(2);*

*Caregivers in Decline. Report of Findings, Evercare. 2006;*

*Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving. AARP Public Policy Institute.*

*June 2007;*

*Family Caregivers-What they Spend, What they Sacrifice. Evercare, November 2007.*



# Continuum of Care Perspective

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- *How do we responsibly value one form of care over another?*
- *Is there a need to do so?*
- *If we consider the caregiving continuum, then what matters more is a true understanding of costs and benefits for all caregivers in an effort to build towards a better care economy.*





# References

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- Arno et al, Health Affairs, 1999
- Arno PS, House J, Sohler N, Schechter C, Viola, D. The Impact of Social Security on Mortality Among the Elderly. Under review.
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- Aging: Evidence and Action,” held at the International Association of Gerontology’s 17th World Congress of Gerontology, Vancouver, July 5, 2001.
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- U.S. Dept. of Commerce, Bureau of the Census, 2004. Table 2a. Projected Population of the US by Age and Sex: 2000 to 2050. Washington, DC.