

# A Profile of Caregiving in the Civilian Population

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# Our research perspective & interests

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- Our work began years ago when we began valuing the benefits and costs of informal caregivers
- We had traditionally focused on the impact of caregiving on the elderly population, in particular women
- Recently we have focused on the impact of the disabled population as they age



# Profile:

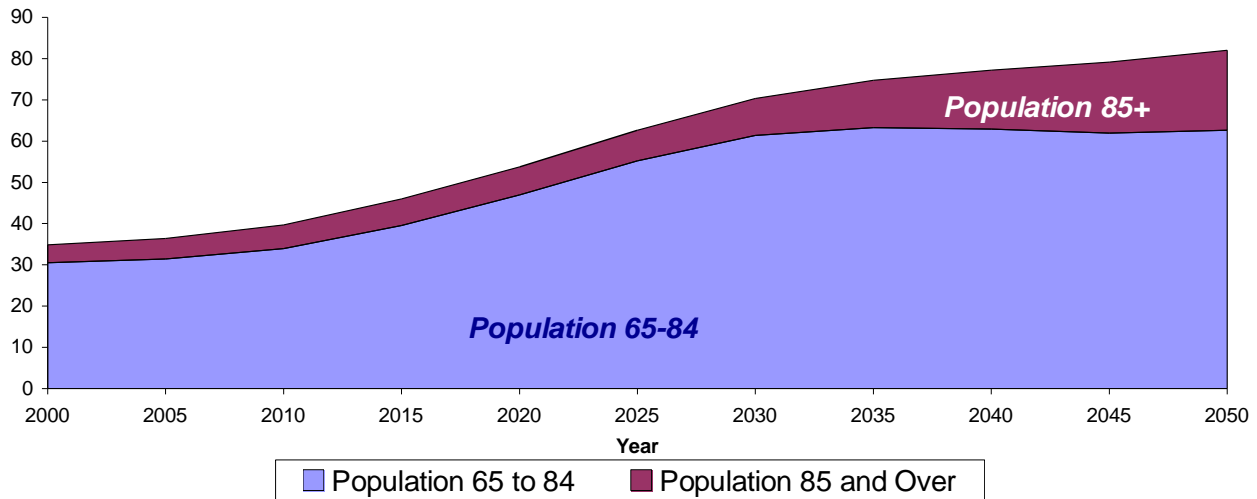
## Caregivers and who they care for

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- Socioeconomic consequences affect caregivers and care recipients:
  - Income
  - Education
  - Race/Ethnicity
  - Gender
  - Age
  - Marital Status
  - Socialization

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

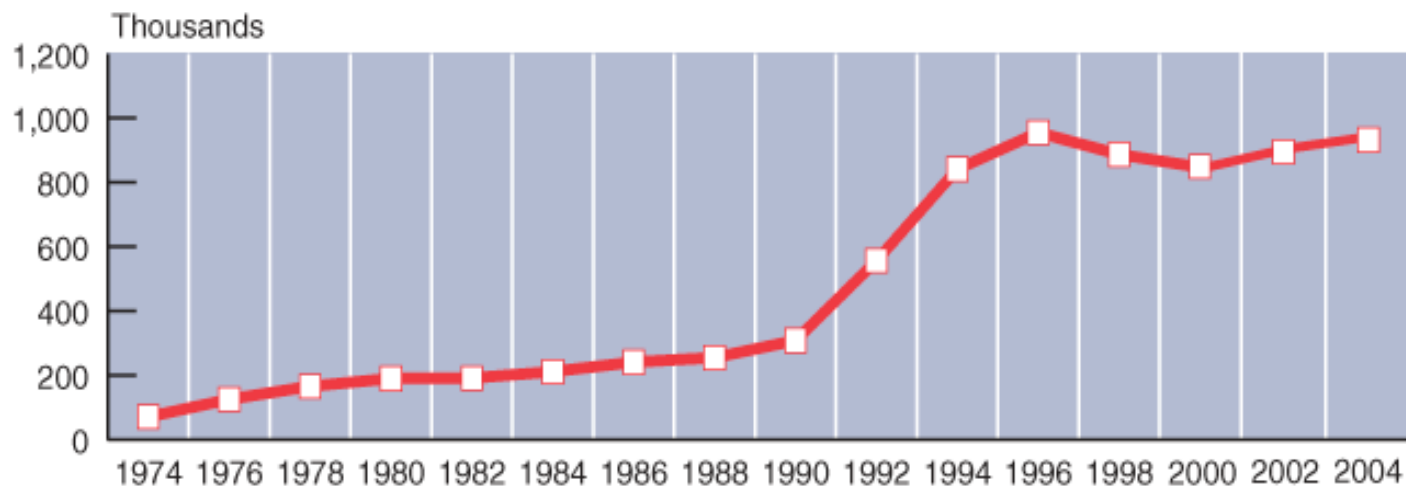
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U.S. Dept. of Commerce, Bureau of the Census, 2004

# Increase in Number of Disabled Children

***Number of children under age 18 receiving SSI, selected years***





# 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



# More care needed

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- Number of elderly caregivers looking after disabled offspring is increasing
- Today, about 76% of the 4.3 million people with developmental disabilities live at home, a quarter of them cared for by a family member who is at least 60 years old.



# More affordable care needed

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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



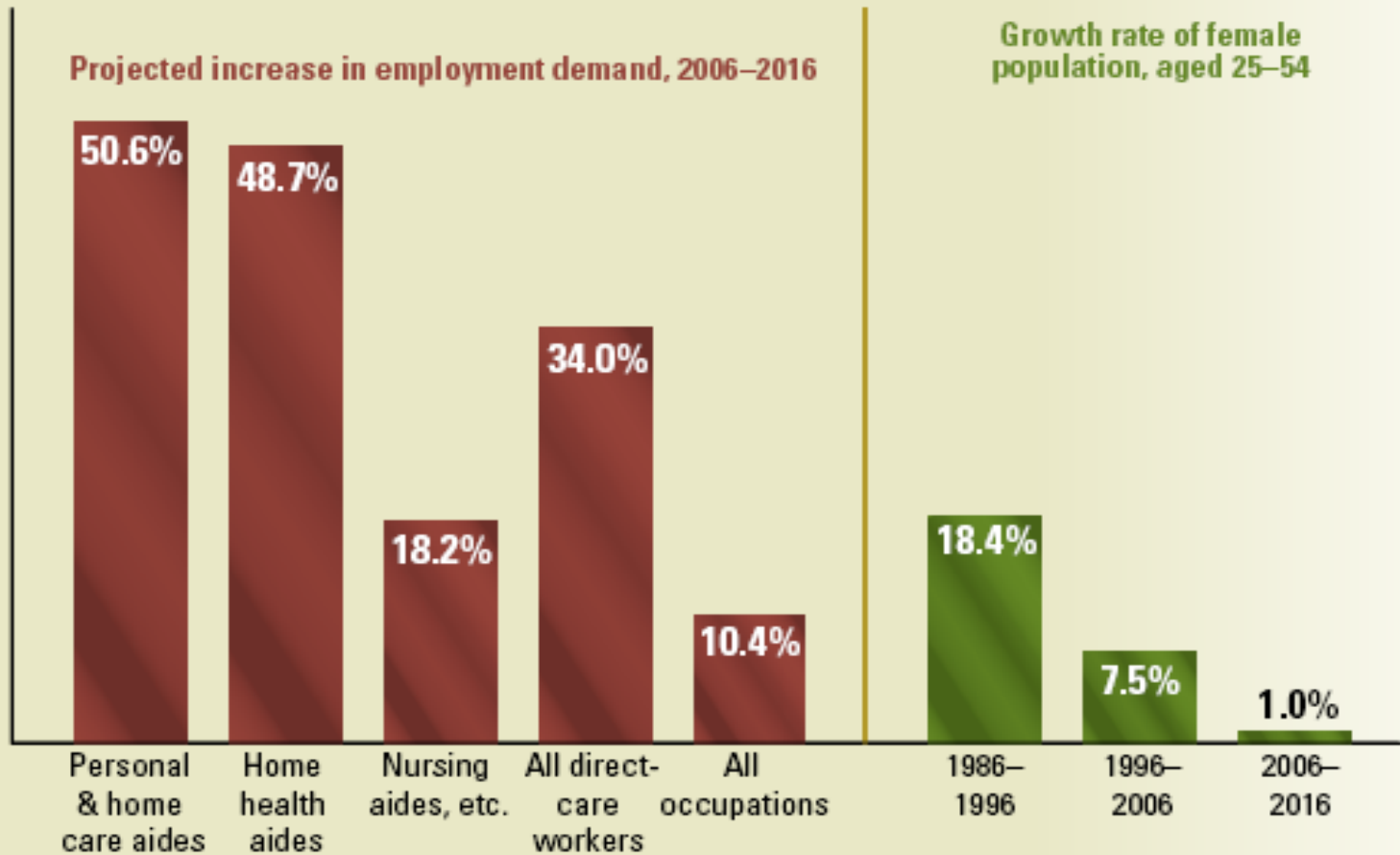


# More affordable care needed

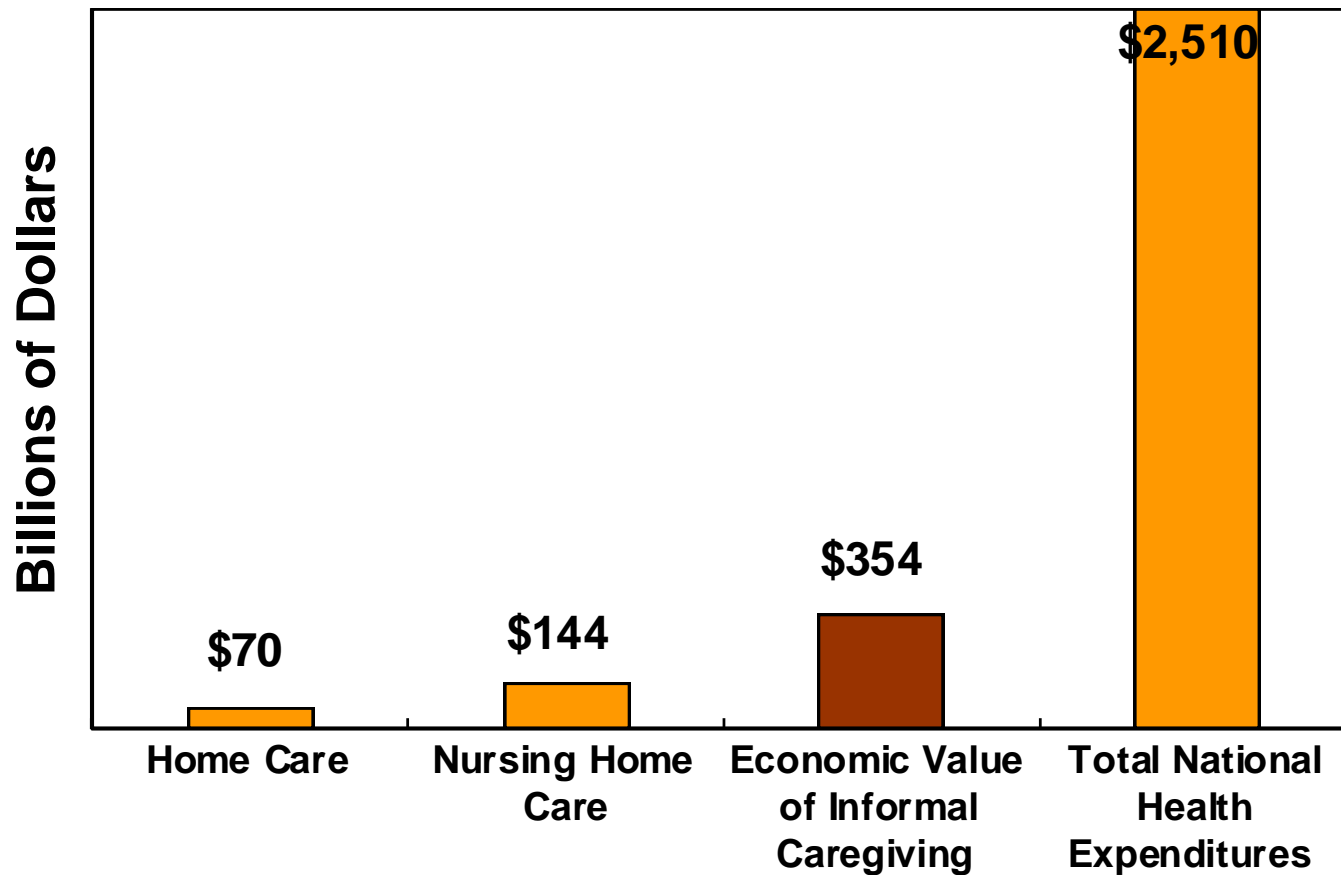
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- Labor force participation rates for women have leveled off
- Growth in household incomes has also leveled off as a result
  - The economic costs of caring for family members are rising
  - Caregiver options are fewer as labor supply for formal caregivers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

## Demand for Direct-Care Workers Is at an All-Time High but Growth in Core Female Labor Supply Is Now Stagnant



# 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**



# 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



# A better care economy

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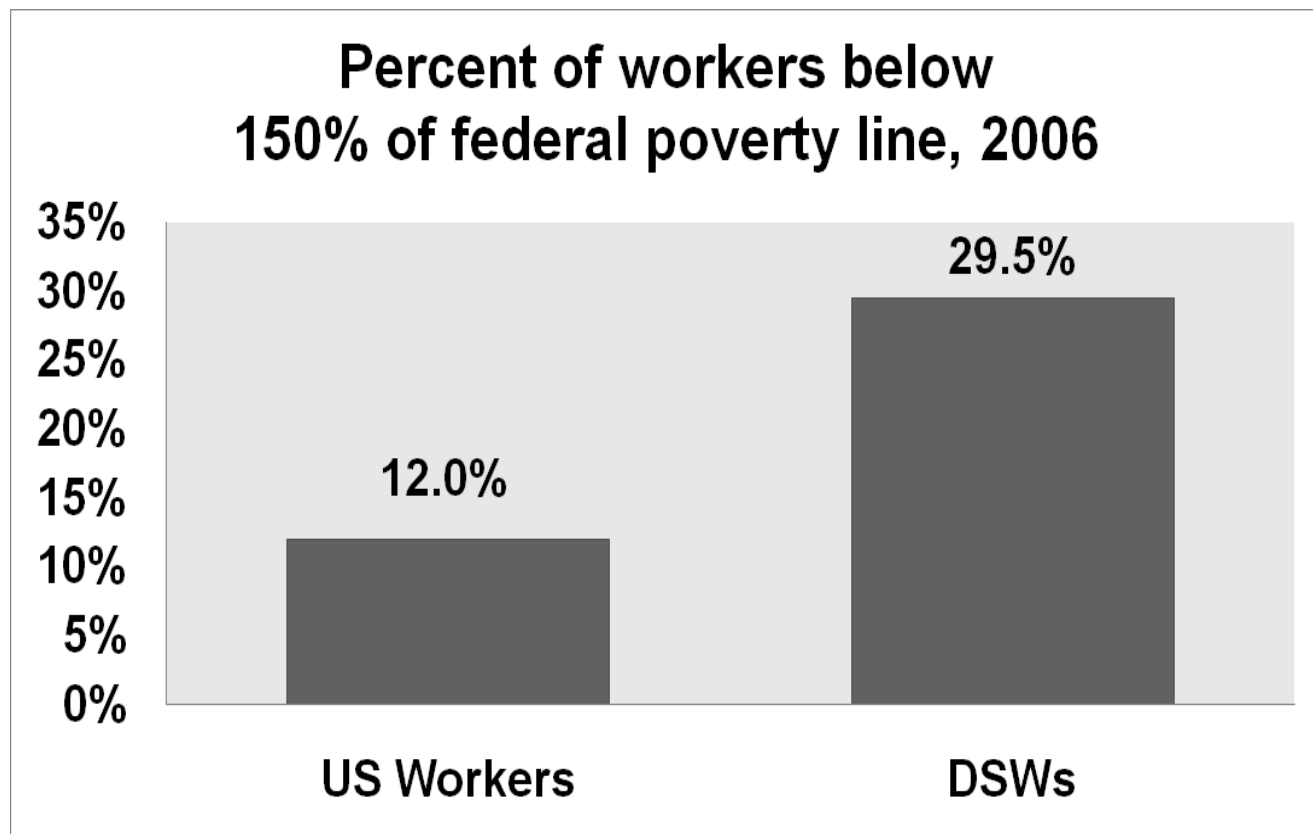
- Policy initiatives must be threefold:
  - Make care giving professions an attractive career choice
  - Compensate direct and indirect costs of informal caregivers
  - Consider the continuum of care as a mix of informal, formal and long term care

# Home Health Aides: Trends in Real Wages



Source: PHI analysis of CPS 2007

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



# 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.*

# Compensate 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 of military personnel: similar issues

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Gaps in services and the issue of more fully addressing the needs of caregivers has also been discussed in the President's Commission on Care for America's Returning Wounded Warriors (Dole/Shalala) and the Veterans Disability Benefits Commission (VDBC). Recommendations from these Commissions include: extending TRICARE coverage for respite and aid and attendance benefits for seriously injured service members; extending the Family Medical Leave Act coverage to family members of a veteran who has a combat-related injury; the need for additional caregiver training and counseling for family members of seriously injured veterans; extension of the Civilian Health and Medical Program of the Department of Veterans Affairs or CHAMPVA program and creation of a "caregiver allowance" for caregivers of severely injured disabled veterans.


Joy J. Ilem, Disabled American Veterans, February 2008



# 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.



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Today's presentation should  
“motivate the need to  
develop a more complete  
vision of a generous,  
equitable, efficient, and  
sustainable care economy.”

# References

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Supplied upon request.

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