

A Profile of Caregiving in the Disabilities Population

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OBJECTIVE AND BACKGROUND

- We are experiencing an aging population with functional limitations and disabilities;
- Coupled with increasing trends in autism, asthma, pre-term births, obesity and other chronic diseases.
- · Family caregiving profiles are changing:
- Three quarters of the 4.3 million people with developmental disabilities are aging at home under the care of parents or siblings
- There are an estimated 1.4 million youth carers

Objective:

Our objective is to describe the economic impact of informal adult and youth caregivers, not only for the elderly, but for those with disabilities, regardless of age so as to inform public policy and improve the long-term supply and quality of caregiving in the U.S.

 This study is intended to serve as a measure of how vulnerable our care system is and to improve understanding about the true costs and benefits for all caregivers.

METHODS

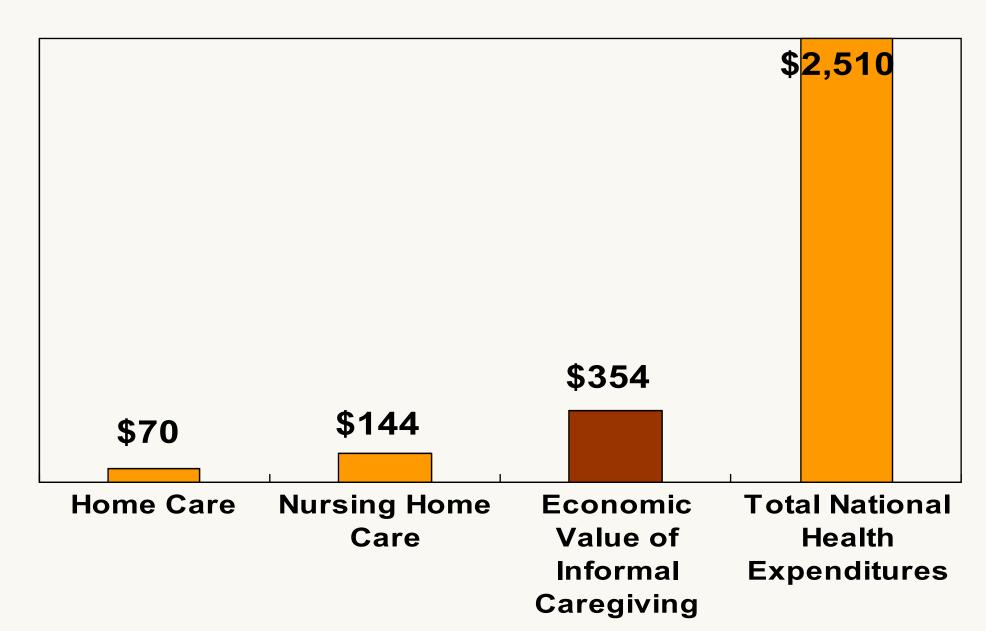
The economic value of youth and adult caregiving for the elderly and those with disabilities is estimated based on prevalence data from two surveys:

- (1) Caregiving in the U.S. 2009
- (2) Young Caregivers in the U.S. 2005

Wage rates are derived from:

- (1) 2009 Metlife Market Survey of Adult Day Care Services & Home Care Costs
- (2) Bureau of Labor Statistics

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



Source: Informal caregiving estimates based on Arno & Viola, 2010; estimates and expenditure data from Office of the Actuary, CMS, Health Affairs, 2009

Economic Value

Economic value of informal caregiving was estimated at \$354 billion in 2009, with youth caregivers under the age of 18 contributing 2.5% of that estimate.

· \$8 billion in unpaid youth caregiving

Burden of Care

Types of Care Recipient

Conditions by Age of Recipient	Recipient Age 0 to 17 (n=173)	Recipient Age 18 to 49 (n=187)	Recipient Age 50 or older (n=1,397)
Short-term physical condition	30%	35%	36%
Long-term physical condition	52%	54%	76%
Emotional or mental health problem	57%	46%	25%
Developmental delay or mental retardation	41%	18%	3%
Learning disability or educational issue	61%	28%	4%
Behavioral issue	45%	31%	10%

Impact of Caregiving

Self-reported health of adult caregivers declines the longer they provide care;

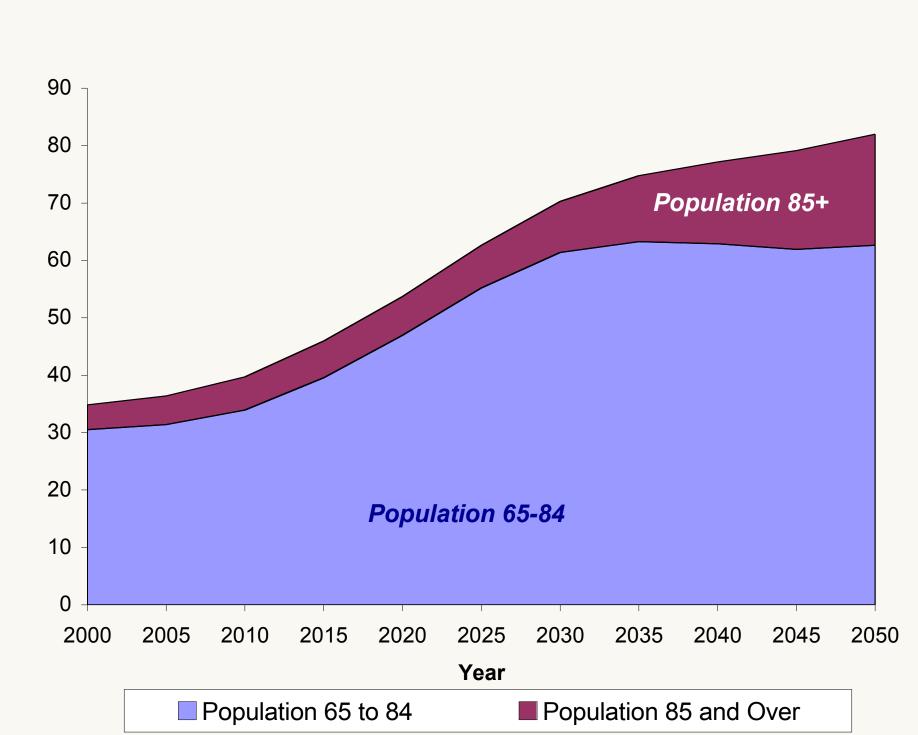
17% report **fair or poor health** compared to 13% of the US adult population

31% of adult, 58% of 8 to 11 year old, and 61% of 12-18 year old caregivers report **stress**, **anxiety or depression**

70% of adult caregivers report making work accommodations due to caregiving; 53% say that they lose time with friends and family

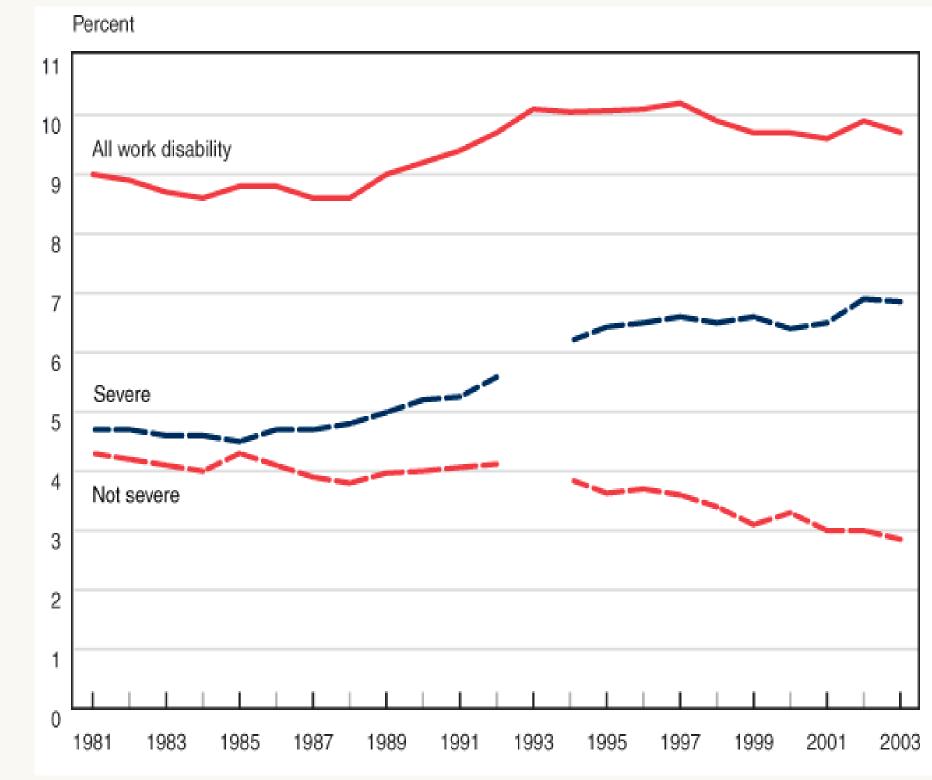
Close to 50% of youth caregivers report **not submitting a homework assignment** and 20% report **missing school or after-school activity**

Aging Population: Limitations, Chronic Conditions

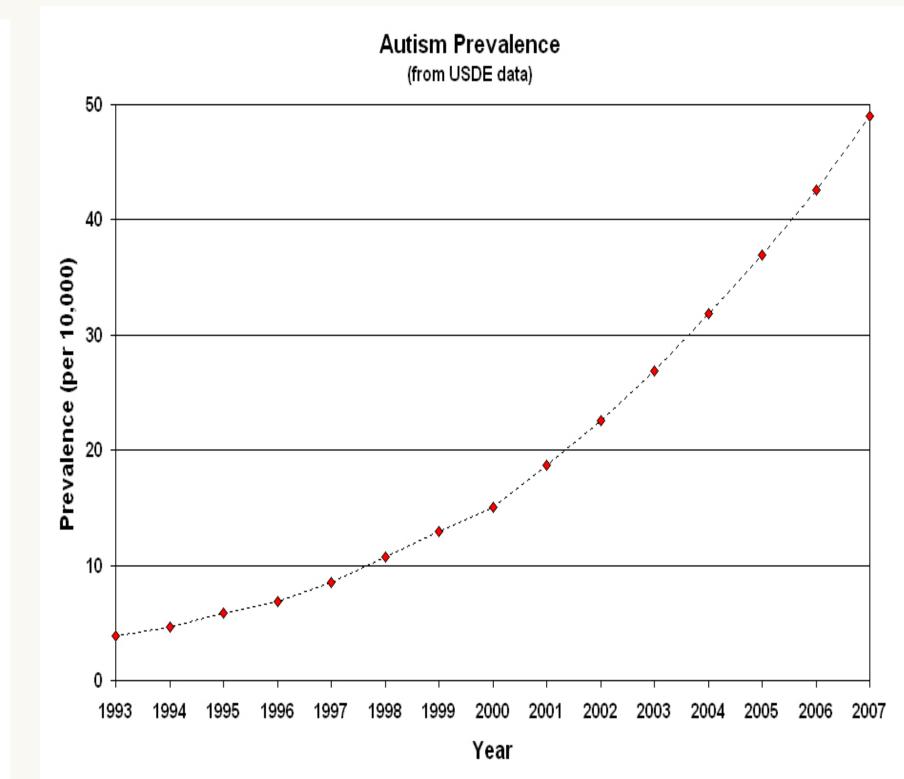


Prevalence of Work Disability for Persons Aged 16–64, US

RESULTS



Autism Prevalence, 1993-2007



CONCLUSION

- Increased strain on an already vulnerable care system due to increasing chronic disease and disability among all age groups.
- Different consequences for adult and child caregivers
- No national programs for financing care by family members
- Support services made through Administration on Aging (but only 40% of states participate)
- Must determine when and how to intervene on behalf of caregivers.
- "...societies need to prepare for a more rational and equitable distribution of sacrifice in caring..."