

# **ARE THE STARS ALIGNING FOR ICF IN THE UNITED STATES?**

---

**Lisa I. Iezzoni, MD, MSc  
Institute for Health Policy  
Massachusetts General Hospital  
Harvard Medical School  
June 10, 2009**

**Thanks to John Hough  
and Marjorie Greenberg**

**U.S. health care  
system could not  
function without  
coded data.**

# **CODED DATA**

---

- **Health care delivery requires:**
  - **Diagnosis codes**
  - **Procedure codes**
- **Codes used to determine:**
  - **Payment levels (MS-DRGs, HCCs for Medicare Advantage plan payment)**
  - **Quality metrics (mortality rate risk adjustment)**
  - **Monitor service use, cost patterns**
  - **Monitor public health concerns**

International Classification of Diseases  
9th Revision-Clinical Modification

# ICD-9-CM

for Hospitals & Payers

Volumes 1, 2 & 3

# 2008

Professional Edition

Clinical  
Management  
Institute

# ICD

---

- ICD-9-CM adopted in 1979
- In 2009, ICD-9-CM has limitations
- Most other countries have moved to ICD-10
- *Federal Register* notice August 22, 2008: U.S. will start using ICD-10-CM for coding diagnoses October 1, 2013

**Need to know more  
about how persons  
are functioning,  
participating in  
activities of daily life.**

# ICF

International  
Classification of  
Functioning,  
Disability  
and  
Health



World Health Organization  
Geneva



# 2001 ICF ENDORSEMENT

---

- 54<sup>th</sup> World Health Assembly (WHA54.21)
- Universal endorsement for:
  - Research
  - Surveillance
  - Reporting
- “As appropriate in Member States”
- Children and Youth Version (ICF-CY) 2007

**ICF has never  
gained traction in  
the United States.**



**What are key  
leverage points?**

# ALIGNING FORCES

---

- 1. Social forces**
- 2. Demographic forces**
- 3. Consequences of health care reform**
  - **Monitoring and maintaining quality of care**
  - **Health information technology (HIT)**
- 4. Public health focus on determinants of health**
  - **Disparities in health and health care**
- 5. Growing recognition of ICF in U.S.**

**The concept of functional status ... applies to all persons, regardless of age, physical or mental condition, or other characteristic.**

**NCVHS Report, 2001, p. 3**

# Societal Forces





**“Disability is a  
lonely state.”**



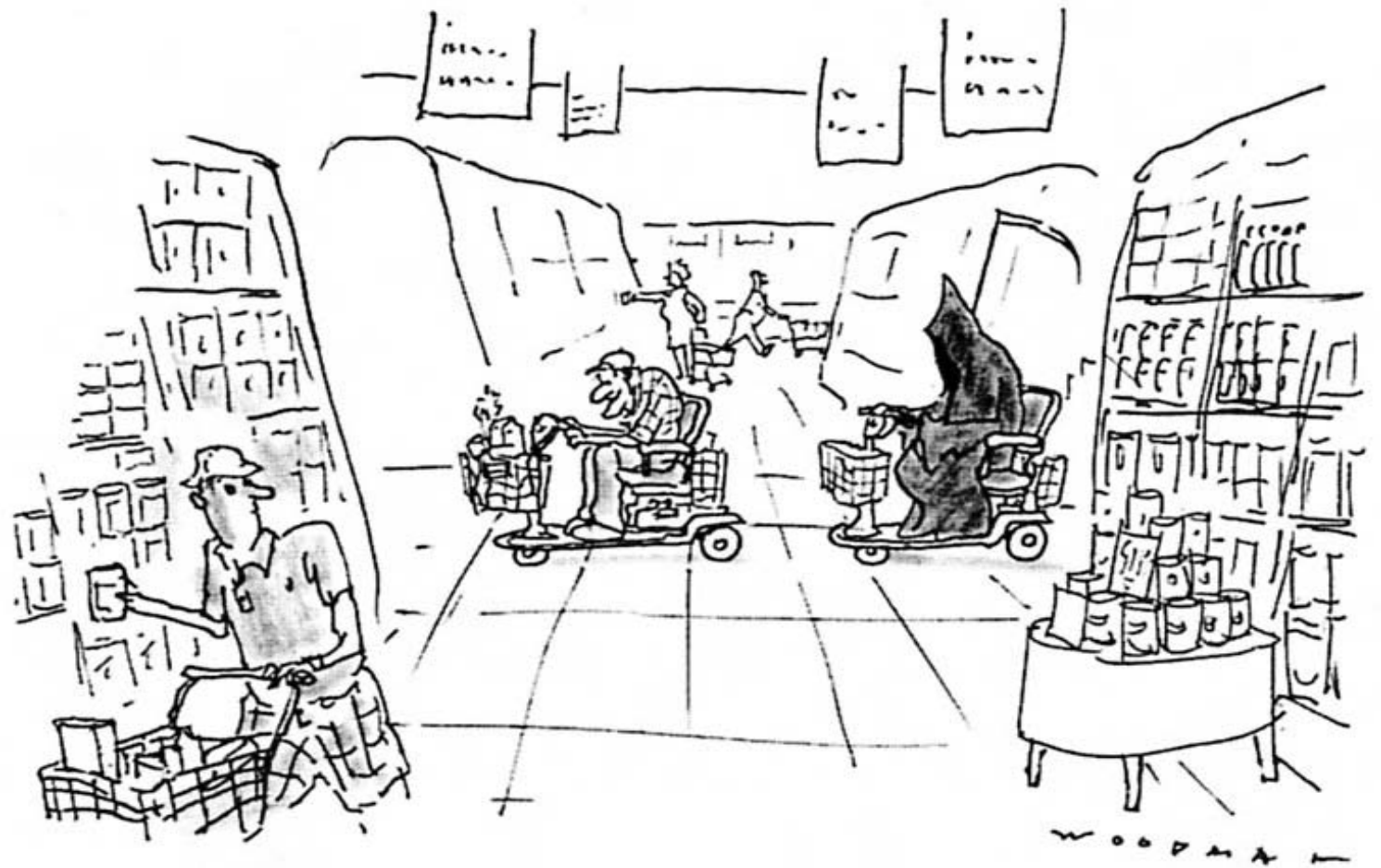












PRICE \$4.95

APRIL 19 & 26, 2004

# THE NEW YORKER





**Accommodations  
require that  
disability be known  
and noticed.**





Copyright Josh Anderchek (2005)

**Code in a medical record  
could alert staff to  
patient's needs.**











# Demographic Forces

**Across the life span,  
Americans are living  
with growing numbers  
of chronic conditions  
and disabilities.**

# EPIDEMIOLOGY

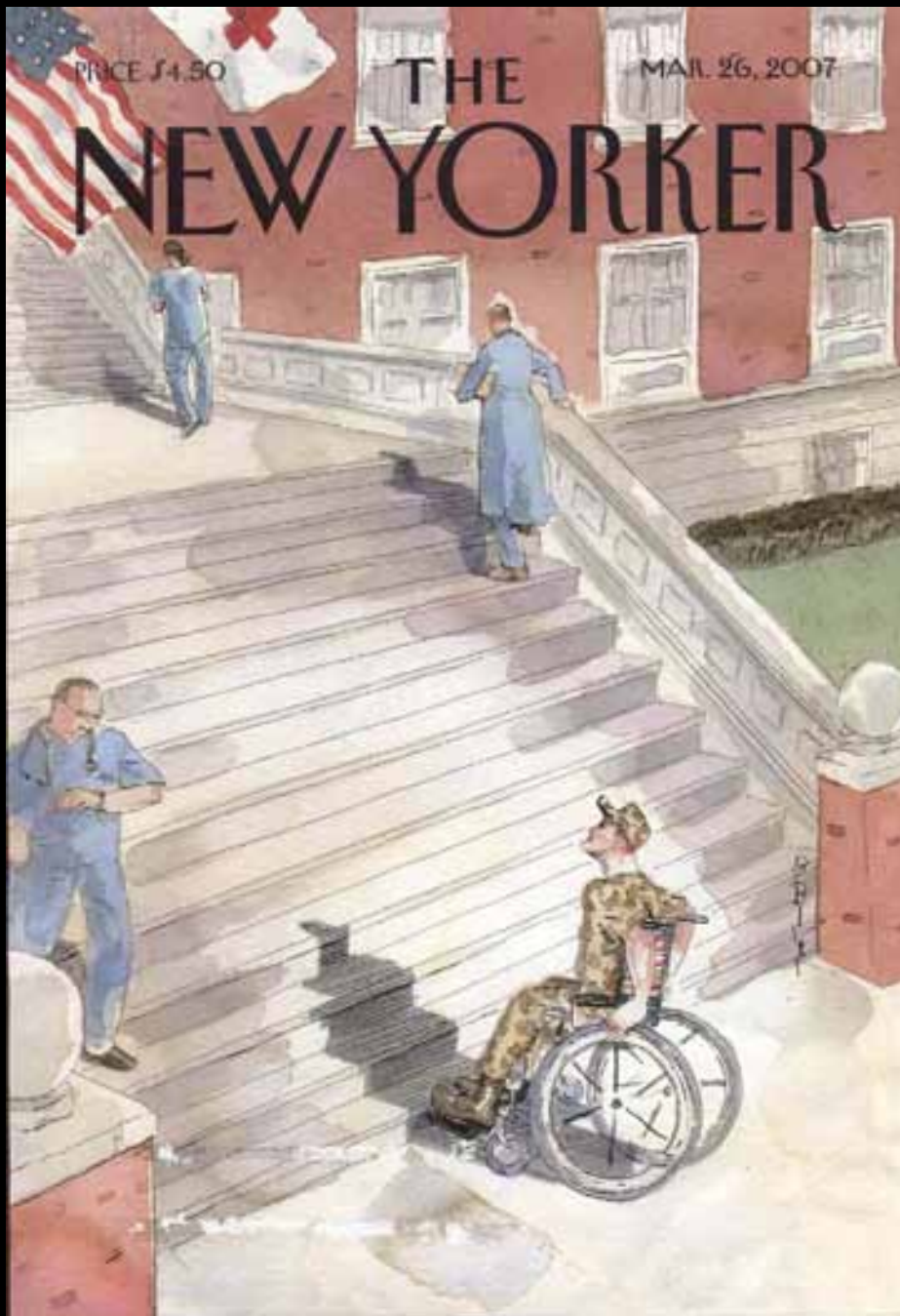
---

- 40-54 million Americans
- Disability rates rise with age
  - 5-15 years: 6%
  - 16-20 years: 7%
  - 21-64 years: 13%
  - 65-74 years: 30%
  - 75+ years: 53%

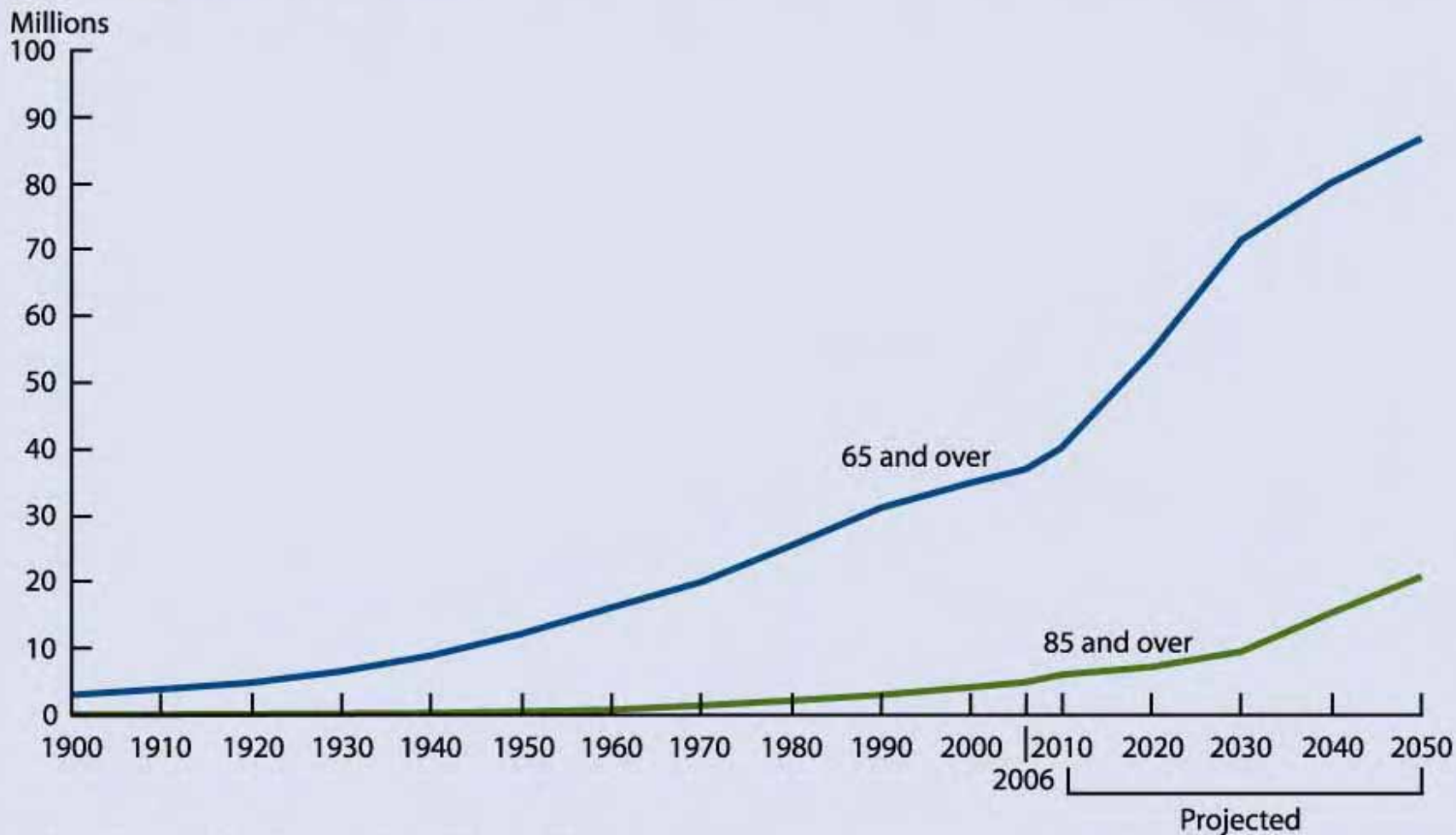
PRICE \$4.50

MAIL 26, 2007

# THE NEW YORKER



## Number of people age 65 and over, by age group, selected years 1900–2006 and projected 2010–2050

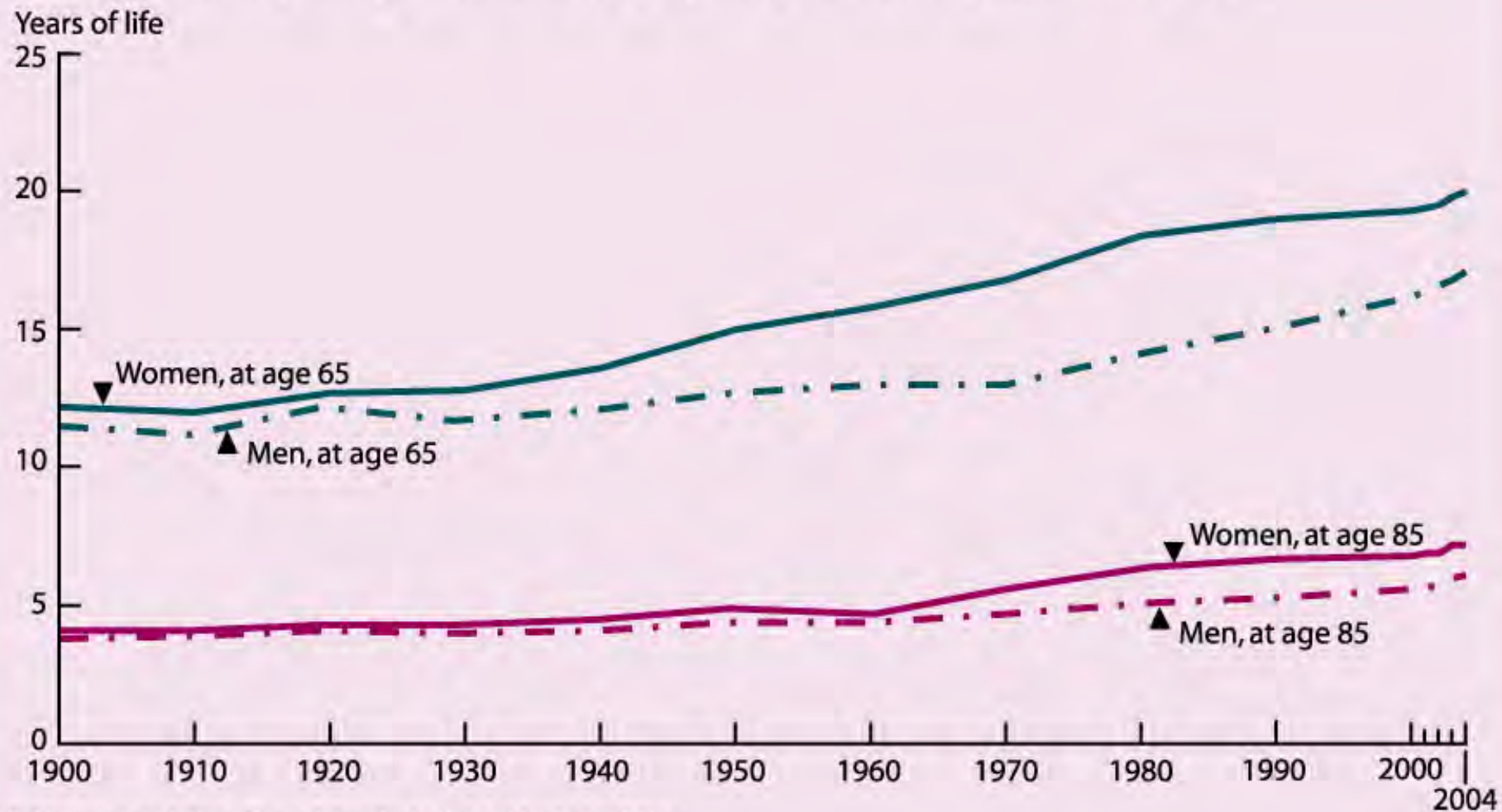


Note: Data for 2010–2050 are projections of the population.

Reference population: These data refer to the resident population.

Source: U.S. Census Bureau, Decennial Census, Population Estimates and Projections.

## Life expectancy at ages 65 and 85, by sex, selected years 1900–2004



Reference population: These data refer to the resident population.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System.



**Disease and  
disability are  
distinct concepts,  
although they often  
coexist.**

# CAUSAL LINKS

---

- **Disease frequently contributes to disability**
  - Osteoarthritis → impaired walking
  - Diabetes → vision problems
- **Disability can cause new diseases**
  - Spinal cord injury → urosepsis, pressure ulcer
- **Chronic conditions → rising disability prevalence among Americans**
  - Arthritis (#1), back problems (#2), heart troubles (#3)

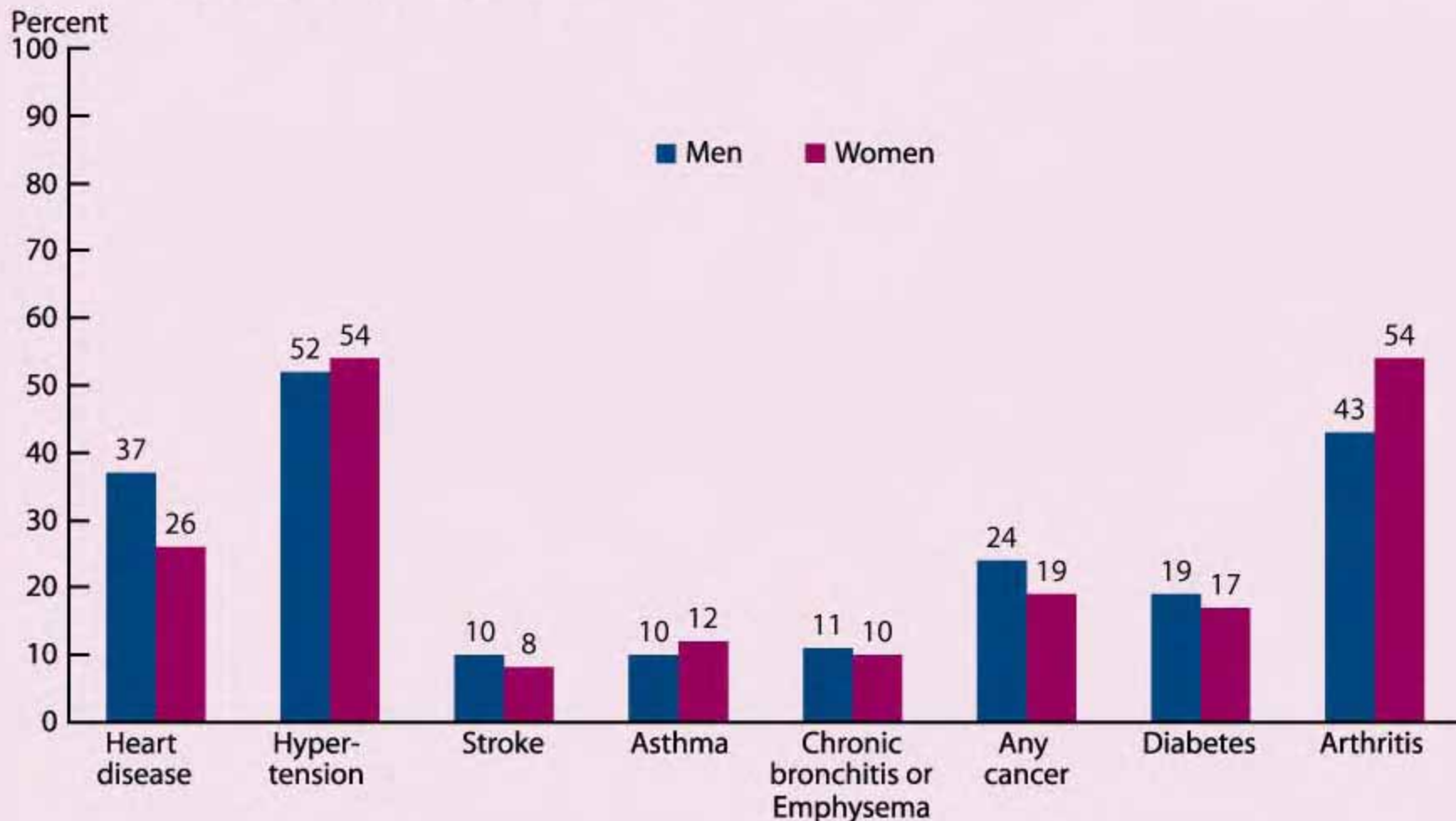


# AGING-RELATED IMPAIRMENTS

---

- **Vision: presbyopia, glaucoma, macular degeneration**
- **Hearing: presbycusis**
- **Cognitive function: Alzheimer's, organic brain dysfunction**
- **Physical function: arthritis, back problems, diabetes, stroke, cardiorespiratory diseases, etc.**

## Percentage of people age 65 and over who reported having selected chronic conditions, by sex, 2005–2006

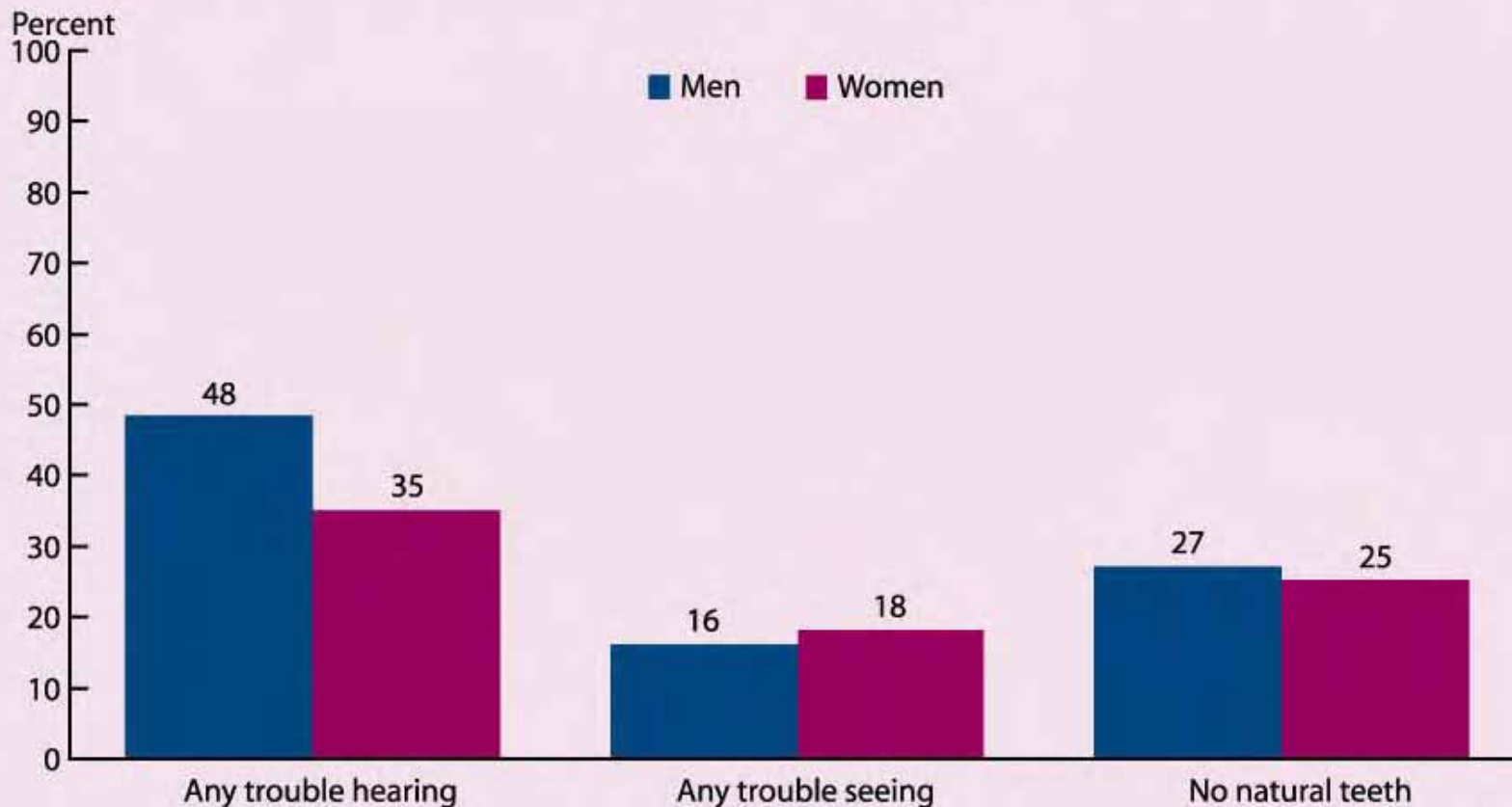


Note: Data are based on a 2-year average from 2005–2006.

Reference population: These data refer to the civilian noninstitutionalized population.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.

## Percentage of people age 65 and over who reported having any trouble hearing, any trouble seeing, or no natural teeth, by sex, 2006

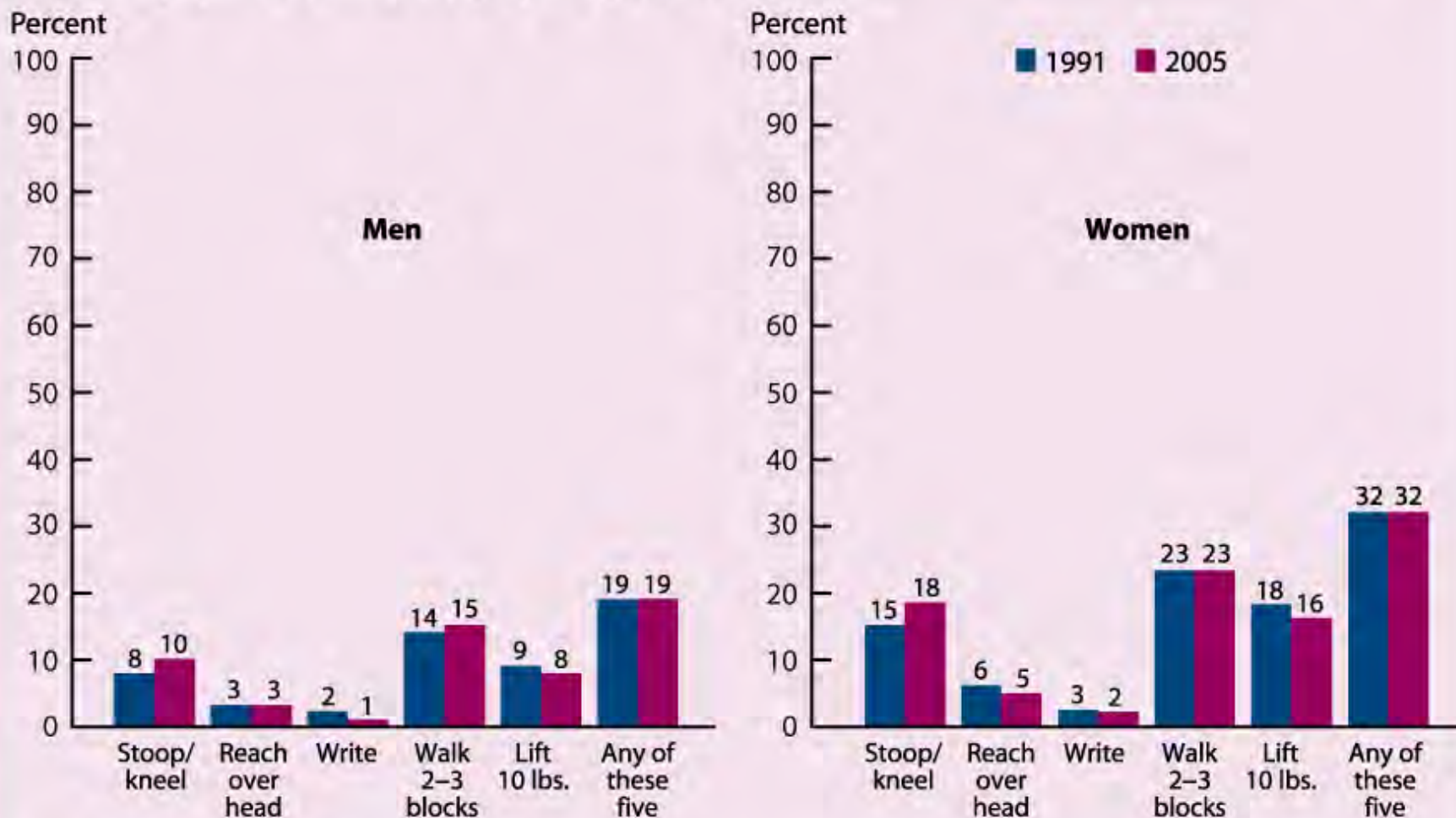


Note: Respondents were asked "Which statement best describes your hearing without a hearing aid: good, a little trouble, a lot of trouble, deaf?" For the purposes of this indicator the category "Any trouble hearing" includes "a little trouble, a lot of trouble, and deaf." Regarding their vision, respondents were asked "Do you have any trouble seeing, even when wearing glasses or contact lenses?" The category "Any trouble seeing" also includes those who in a subsequent question report themselves as blind. Lastly, respondents were asked, in one question, "Have you lost all of your upper and lower natural (permanent) teeth?"

Reference population: These data refer to the civilian noninstitutionalized population.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey.

## Percentage of Medicare enrollees age 65 and over who are unable to perform certain physical functions, by sex, 1991 and 2005



Note: Rates for 1991 are age adjusted to the 2005 population.

Reference population: These data refer to Medicare enrollees.

Source: Centers for Medicare and Medicaid Services, Medicare Current Beneficiary Survey.

**“The ‘baby boomers’ are coming. We’re not going to warehouse them in nursing homes. These ‘boomers’ are not going to go quietly into the night.”**

THE FUTURE OF  
**DISABILITY**  
IN AMERICA

INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES

2013



# VIRTUALLY EVERYONE

---

**“... Disability in America is not a minority issue ... Disability affects today or will affect tomorrow the lives of most Americans ... People born in 1946 will turn age 65 in 2011. The future of disability in America will ... depend on the country’s response to this demographic shift.”**

***Future of Disability in America 2007***

# Health Care Reform



# HEALTH CARE AND THE “FIERCE URGENCY OF NOW”

---

“Our families will never be secure, our businesses will never be strong, and our Government will never again be fully solvent until we tackle the health care crisis.”



**President Bill Clinton, State of the Union  
Address, February 17, 1993**



**President Barack Obama**

**This year, we must do more than discuss. We must act. ... America's future demands it.**

**Obama, June 2, 2009**

**\$2.4 trillion**

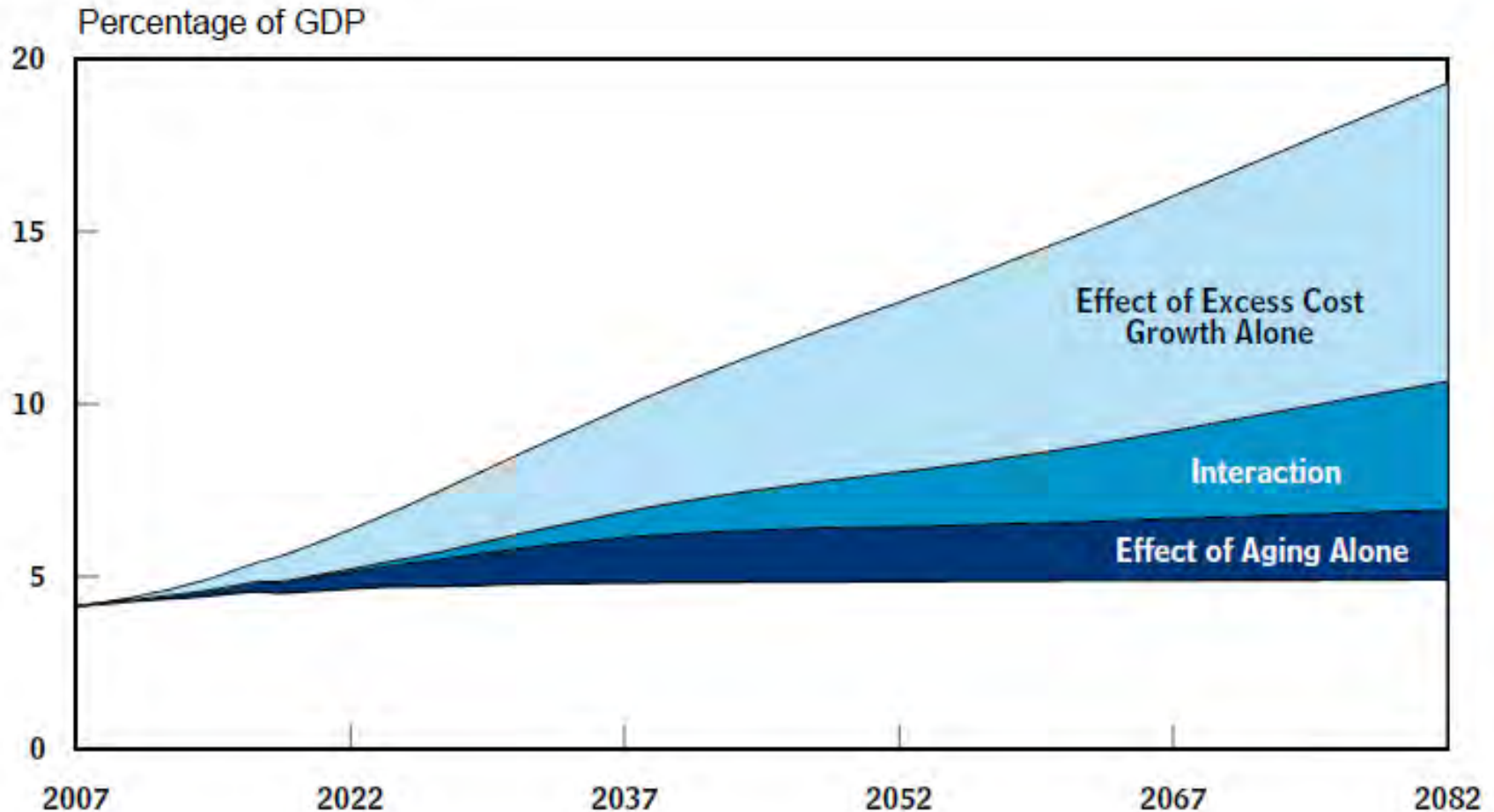
**Without a serious,  
sustained effort to reduce  
the growth rate of health  
care costs, affordable  
health care coverage will  
remain out of reach.**

**Obama, June 2, 2009**

# Estimated Contributions of Selected Factors to Long-Term Growth in Real Health Care Spending per Capita, 1940 to 1990

Percent			
	Smith, Heffler, and Freeland (2000)	Cutler (1995)	Newhouse (1992)
<b>Aging of the Population</b>	2	2	2
<b>Changes in Third-Party Payment</b>	10	13	10
<b>Personal Income Growth</b>	11-18	5	<23
<b>Prices in the Health Care Sector</b>	11-22	19	Not Estimated
<b>Administrative Costs</b>	3-10	13	Not Estimated
<b>Defensive Medicine and Supplier-Induced Demand</b>	0	Not Estimated	0
<b>Technology-Related Changes in Medical Practice</b>	38-62	49	>65

# Sources of Growth in Projected Federal Spending on Medicare and Medicaid: CBO Projections





# PROCESS OVERVIEW

---

- **Obama's strategy: address roots of 1994 failure of Clinton's initiative**
- **Give Congress broad principles about what plan must have**
- **Involve all stakeholders as much as possible (e.g., insurers, consumers)**
- **Let Congress do hard work of negotiating plan**

# PRINCIPLES #1

---

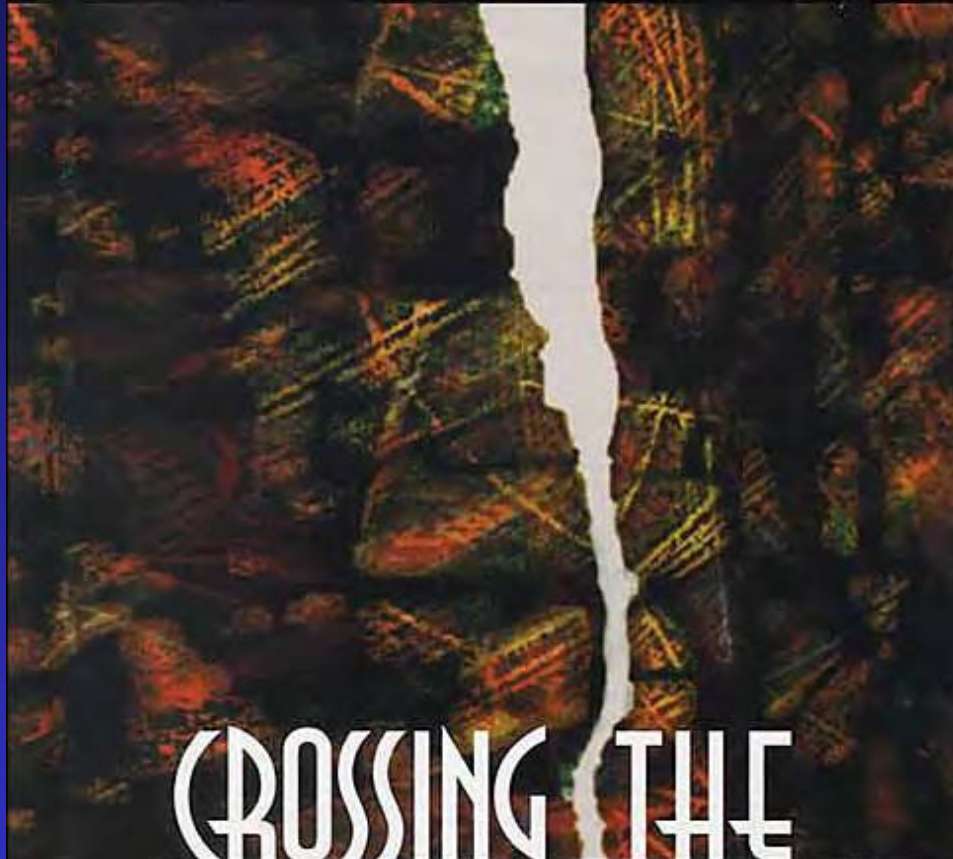
1. **Protect financial health of families**
2. **Make health insurance affordable**
3. **“Aim for” universality (uneasy about mandates)**
4. **Make coverage portable**

# PRINCIPLES #2

---

5. Guarantee choice
6. Invest in prevention and wellness care
7. Improve patient safety and quality of care
8. Maintain long-term financial sustainability

I N S T I T U T E   O F   M E D I C I N E



# CROSSING THE QUALITY CHASM

A New Health System for the 21st Century

# QUALITY EDICT

---

- Demands data: cannot manage what cannot measure
- Diagnostic and procedural data only go so far
- Need to know patients' functional status
- Ideally also need to know patients' preferences for care

CENTERS FOR MEDICARE & MEDICAID SERVICES

## Medicare's Hospital Compare



### Need a Hospital? Take Time to Compare

*Some hospitals do a better job of taking care of  
patients than others.*



[www.medicare.gov/hospital](http://www.medicare.gov/hospital)

# RISK ADJUSTMENT

---

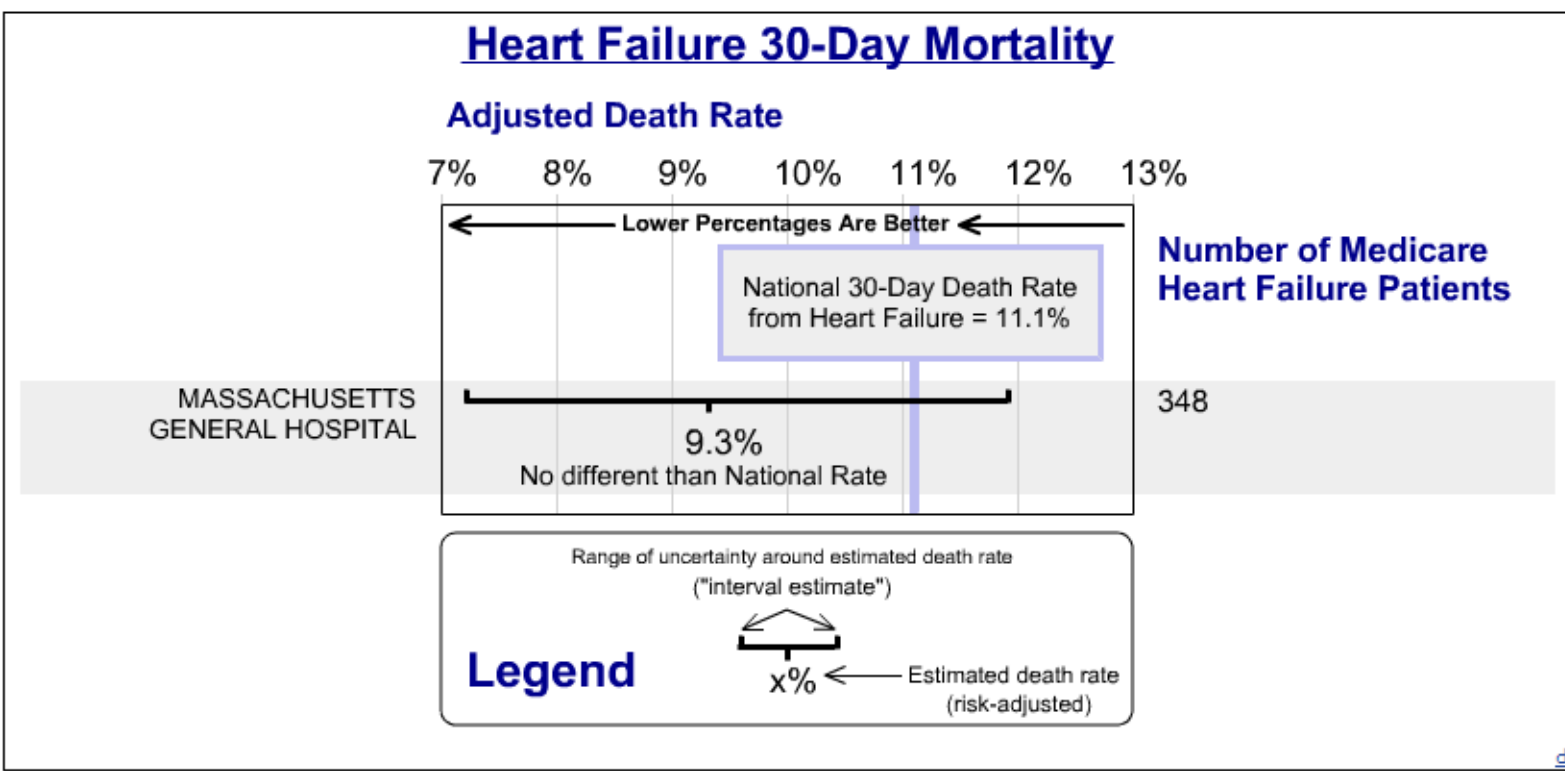
- 30-day, post-admission mortality
- Age, sex
- History of PTCA, CABG, heart failure, MI
- Secondary diagnoses from admission: e.g., diabetes, metastatic cancer, COPD, dementia, protein-calorie malnutrition

Graph 1 of 1

Hide Information

**Heart Failure**

These percentages were calculated from Medicare data on patients discharged between July 2006 and June 2007. They do not include people in Medicare Advantage (managed care) plans or people who do not have Medicare.



**What does this show you?** The graph above shows the estimated 30-day death (mortality) rates for heart failure at each of the hospitals you selected, compared to the national 30-day death rate for all Medicare patients treated for heart failure. The death rates for each hospital shown here have been Risk-Adjusted. This means that they take into account how sick patients were before they were admitted to the hospital.



# **RISK ADJUSTMENT ?'s**

---

- **New York Heart Association Functional Class = critical indicator of risk in heart failure**
- **ICF codes could convey that information**
- **Full information on patients' risks required to avoid penalizing hospitals with sicker patients**

# HOSPICE QUESTIONS

---

- Buffalo, NY, hospital: among worst 35; CHF mortality 4.9% higher than national average (Holloway & Quill, *JAMA* 2007)
- 40% of CHF deaths: DNR, hospice
- Mortality model did not account for DNR, hospice care

# HEALTH INFORMATION TECHNOLOGY (HIT)

---

- American Recovery and Reinvestment Act of 2009
- \$20 million to National Institute of Standards and Technology to work on technical standards, etc.
- “Qualified electronic health record”
  - “Improves health care quality, reduces medical errors, reduces health disparities, and advances delivery of patient-centered care”

# ARRA REQUIRES HIT TO:

---

- Reduce “health care costs resulting from inefficiency, medical errors, inappropriate care, duplicative care, and incomplete information”
- Provide “appropriate information to help guide medical decisions at the time and place of care”

**Information on  
functional status must  
become an integral  
part of electronic  
health record.**

# ELECTRONIC OPTIONS

---

- Can ICF be integrated within standard electronic data elements?
- 2005-2006 work of Consolidated Health Informatics (CHI) initiative
  - Phase II Disability Work Group efforts
- CHI Functioning and Disability Domain; use LOINC® → ICF codes
- NCVHS Report, November 2006

# NCVHS NOVEMBER 2006

---

- “Endorsing ICF as a CHI standard for ... functioning and disability:
  - Inclusion of ICF in UMLS
  - Mapping between ICF and SNOWMED
  - Expanding coded disability content available for use
  - Making ICF available for use ... in standardizing patient assessments ...”

# POST-ACUTE CARE

---

- **Nursing homes: Minimum Data Set (MDS)**
- **Home health agencies: Outcome and Assessment Information Set (OASIS)**
- **Inpatient rehabilitation facilities: Patient Assessment Instrument (IRF-PAI)**



# Public Health



# Healthy People 2010

## Volume I

- Understanding and Improving Health
- Objectives for Improving Health  
(Part A: Focus Areas 1-14)

# Action Model to Achieve Healthy People 2020 Overarching Goals

## Determinants of Health

## Interventions

- Policies
- Programs
- Information



## Outcomes

- Behavioral outcomes
- Specific risk factors, diseases, and conditions
- Injuries
- Well-being and health-related Quality of Life
- Health equity

**Assessment, Monitoring,  
Evaluation & Dissemination**



**Broad social, economic,  
cultural, health, and  
environmental conditions and  
policies at the global, national,  
state and local levels ...**

**Secretary's Advisory Committee 2008**



# Healthy People 2010

## Volume I

- Understanding and Improving Health
- Objectives for Improving Health  
(Part A: Focus Areas 1-14)

**The Surgeon General's  
Call to Action to Improve the  
Health and Wellness of  
Persons with Disabilities  
2005**

U.S. DEPARTMENT OF HEALTH AND  
HUMAN SERVICES  
Public Health Service  
Office of the Surgeon General  
Rockville, MD

# BREAST CANCER

---

- Breast conserving surgery (BCS) for early-stage breast cancer; requires radiation therapy after surgery
- Women with disabilities < age 65:
  - 20% less likely to get BCS
  - If they have BCS, 17% less likely to get radiation therapy
  - 45% more likely to die from breast cancer

*Annals Intern Med* 2006



# CANCER REGISTRY

---

- **Surveillance, Epidemiology, and End Results (SEER) cancer registries, produced by NCI – merged with Medicare claims**
- **Clinical information on tumor type and characteristics, treatments**
- **Nothing on functional status, although oncologists focus on functional status to make treatment decisions: used SSDI**



# National Healthcare Disparities Report



**AHRQ**

Agency for Healthcare Research and Quality  
Advancing Excellence in Health Care • [www.ahrq.gov](http://www.ahrq.gov)

# DISPARITIES REPORT

---

- 1999 Congressional mandate to Agency for Healthcare Research and Quality (AHRQ)
- Report on “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations”
- Includes people with disabilities

# 2007 CONTENT

---

- **Exercise counseling: obese adults**
- **Inappropriate medication use by elderly**
- **Delay receiving needed care**
- **Children with special health care needs**
  - **Delays in care for illness, injury**
  - **Poor communication with health care providers reported by parents**

# REPORT LIMITATIONS

---

- Limited definitions of disability
- Relied largely on self-reported ADL limitations
  - Basic activity limitations
  - Complex activity limitations
- Few reported measures

**Growing Recognition**

# NCVHS REPORTS

---

- **“Classifying and Reporting Functional Status” (2001)**
  - **“ICF is the only existing classification system that could be used to code functional status across the age span” (p. 13)**
- **“Consolidated Health Informatics Standards Adoption Recommendations: Functioning and Disability” (2006)**
  - **“ICF is a CHI-endorsed standard for the functioning and disability domain” (p. 8)**





# UNIFIED MEDICAL LANGUAGE SYSTEM

---

- UMLS National Library of Medicine
- 2009: ICF and ICF-CY terms incorporated into UMLS Knowledge Systems
- Partnership with WHO
- UMLS user can link ICF terms with other classifications, terminologies, vocabularies within UMLS



# OTHER EXAMPLES

---

- **National Institute on Disability and Rehabilitation Research (NIDRR)**
  - Incorporated ICF into NIDRR Logic Model and referenced ICF in defining disability
- **Endorsements by ≈ dozen professional organizations**
- ***Healthy People 2010* (2000): Chapter 6 cited conceptual framework of earlier draft of ICF (ICIDH)**

THE FUTURE OF  
**DISABILITY**  
IN AMERICA

INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES

REPORT OF THE COMMITTEE ON THE FUTURE OF DISABILITY IN AMERICA

# RECOMMENDATION 2.1

---

- NCHS, Census, Bureau of Labor Statistics and others should adopt ICF conceptual framework
- Promote refinements and improvements of ICF
- Interagency Committee on Disability Research

# **DIRECTIONS**

---

- 1. Clarify activity and participation concepts**
- 2. Incorporate quality of life**
- 3. Delineate personal factors**
- 4. Extend classification of environmental factors**
- 5. Incorporate secondary health conditions**
- 6. Add dynamic model reflecting movement across functional states**

# ICF

International  
Classification of  
Functioning,  
Disability  
and  
Health



World Health Organization  
Geneva



**Rationale and  
impetus are building  
– must seize the  
moment**



