INCORPORATING CIVIL RIGHTS PRINCIPLES INTO PUBLIC HEALTH REGULATIONS AT THE STATE LEVEL TO REDUCE HEALTH DISPARITIES BY STRENGTHENING THE HEALTH CARE SYSTEM AT THE COMMUNITY LEVEL

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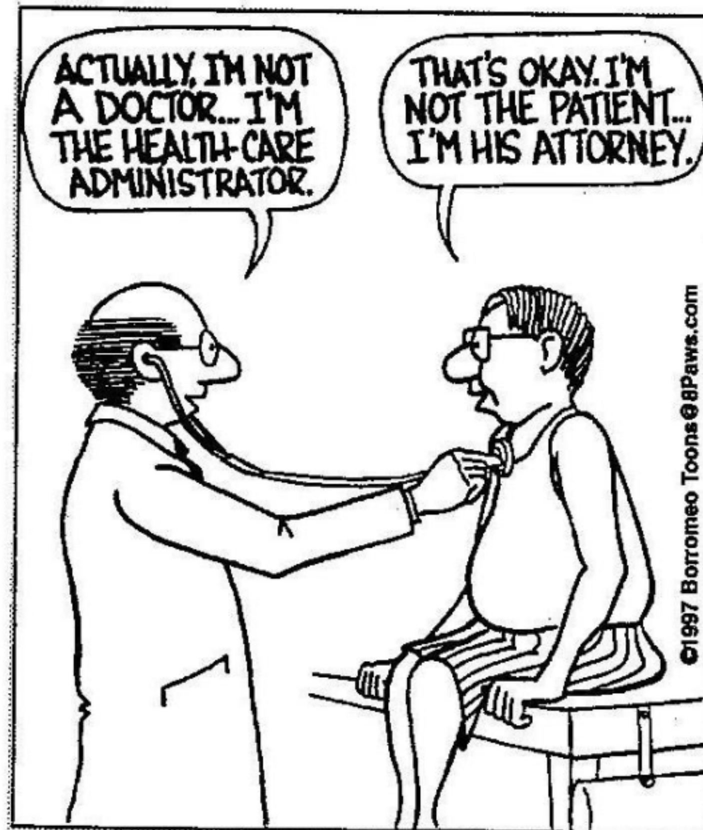
Is health care an industry or a public utility?



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Assumption 1: Lack of system-ness at community level

- Health care system is highly fragmented (e.g. Commonwealth Fund scorecards of health system performance measures in relation to benchmarks)

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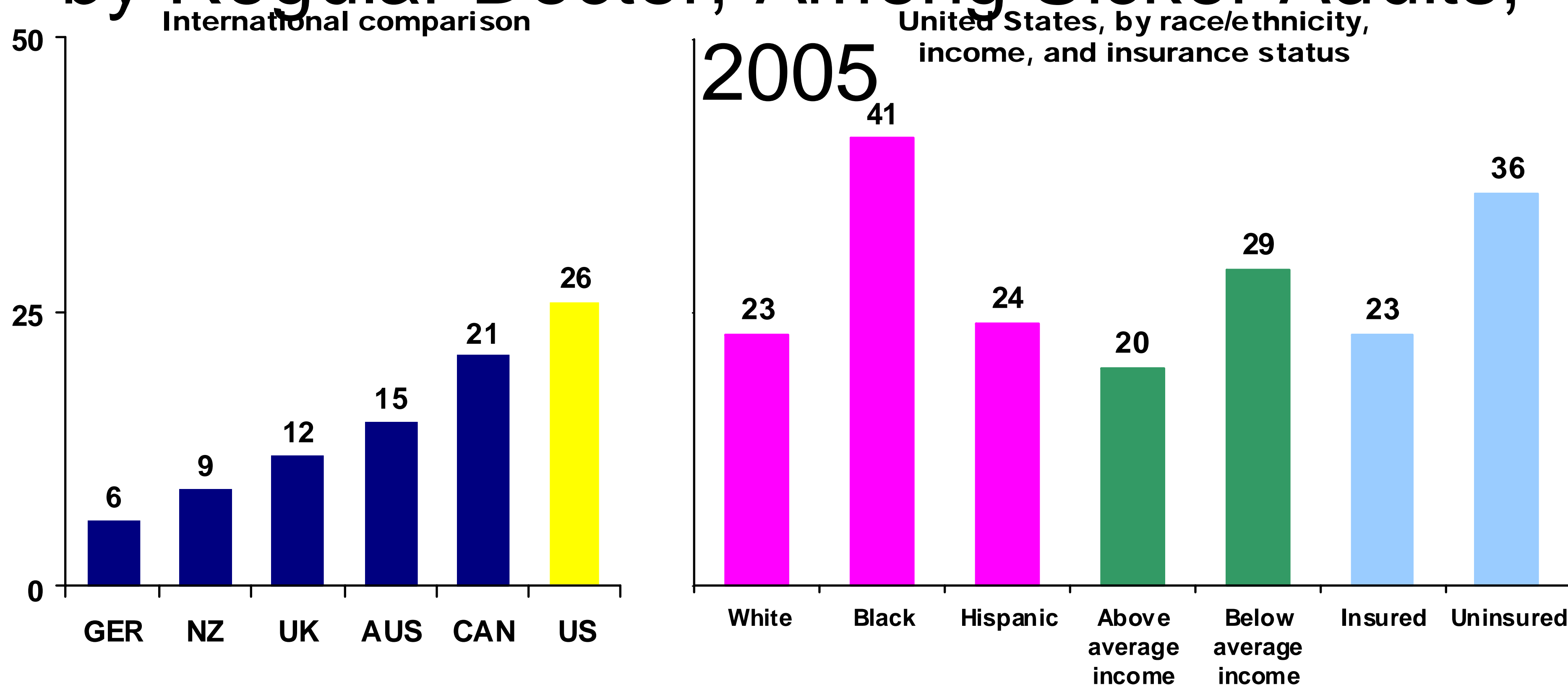
Went to ER for Condition That Could Have Been Treated by Regular Doctor, Among Sicker Adults, 2005



GER=Germany; NZ=New Zealand; UK=United Kingdom; AUS=Australia; CAN=Canada; US=United States.
Data: Analysis of 2005 Commonwealth Fund International Health Policy Survey of Sicker Adults; Schoen et al. 2005a.

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2006

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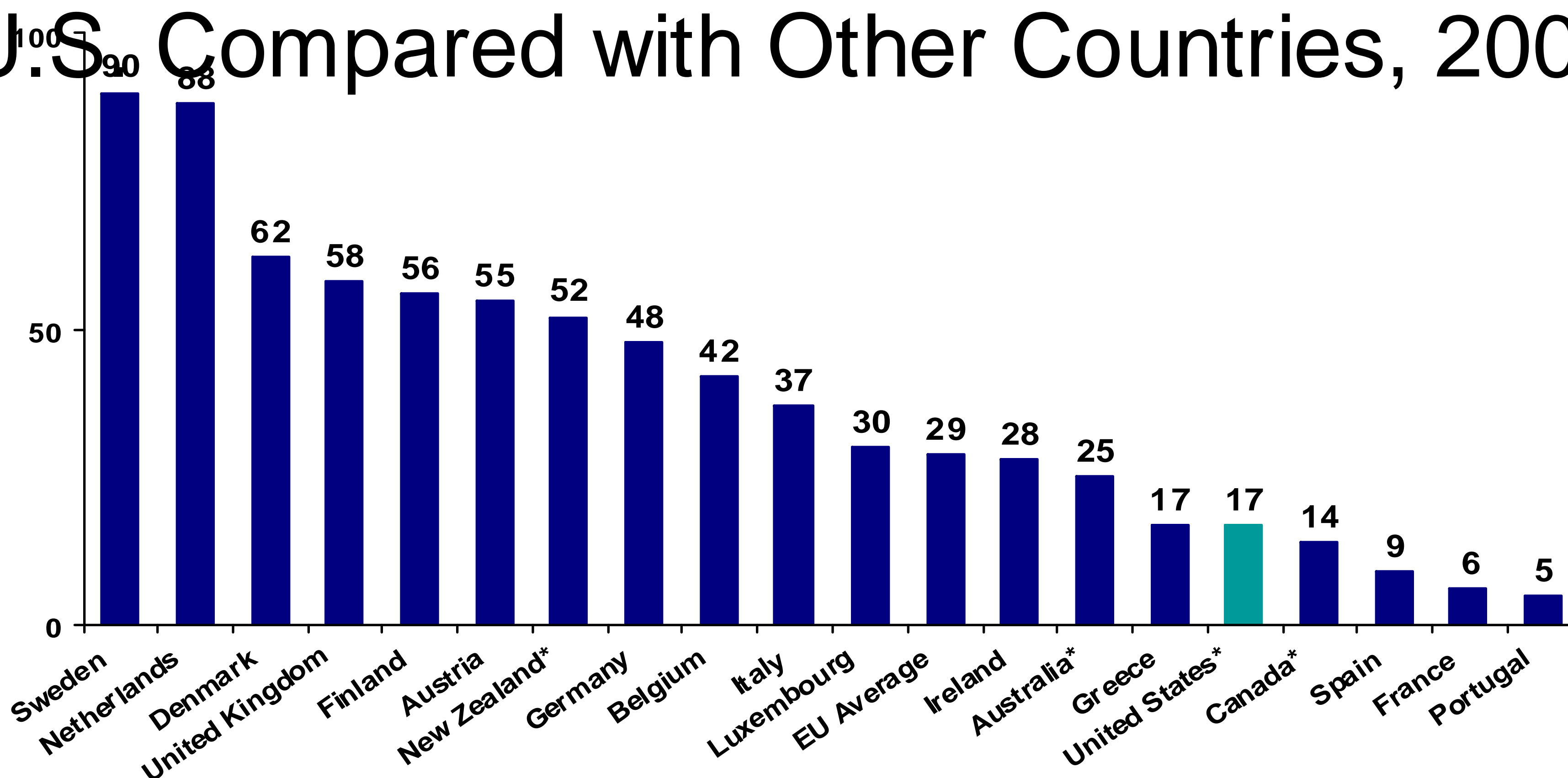
Physicians' Use of Electronic Medical Records, U.S. Compared with Other Countries, 2001



* 2000

Data: 2001 European Union EuroBarometer and 2000 Commonwealth Fund International Health Policy Survey of Physicians (Harris Interactive 2002).

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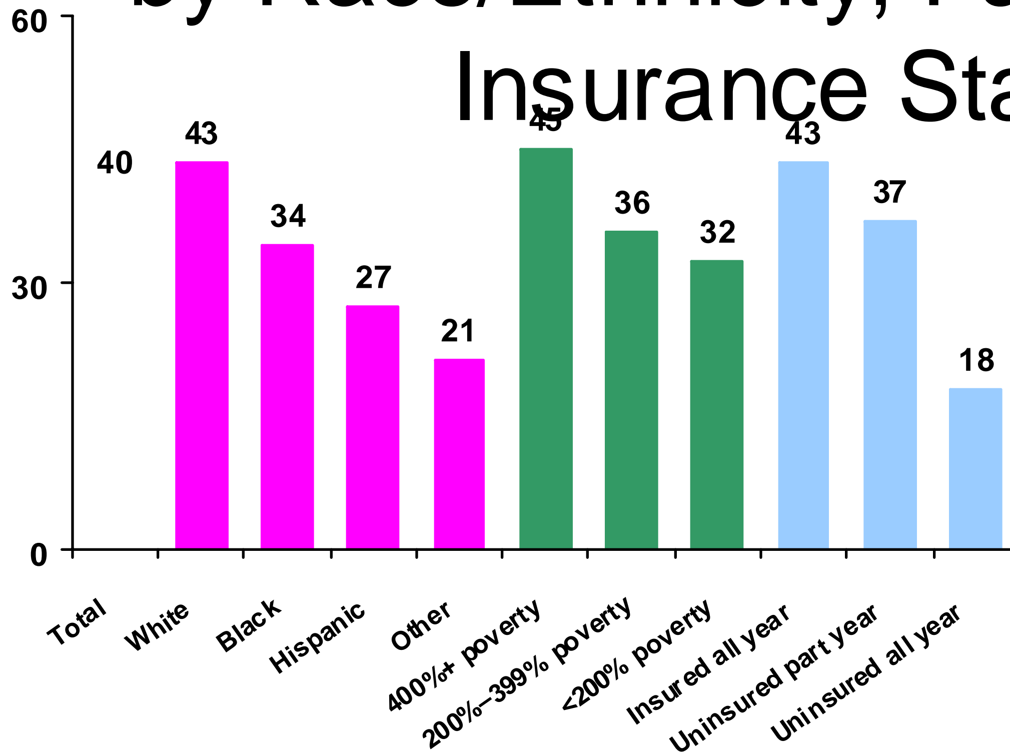
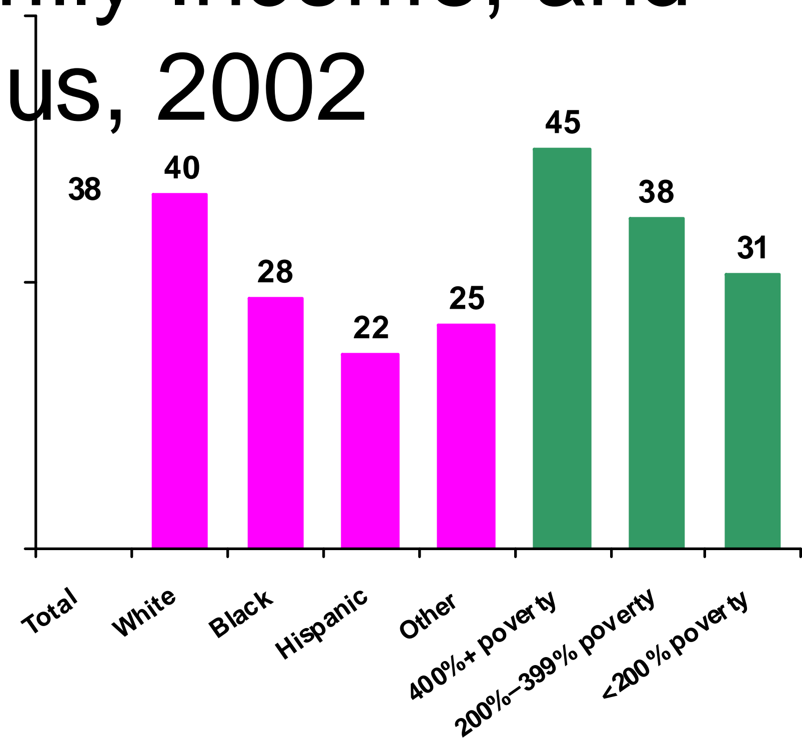
Receipt of Recommended Preventive Care for Older Adults, by Race/Ethnicity, Family Income, and Insurance Status, 2002

Percent of older adults who received all recommended screening and preventive care within a specific time frame given their age and sex*





* Recommended care includes seven key screening and preventive services: blood pressure, cholesterol, Pap, mammogram, fecal occult blood test or sigmoidoscopy/colonoscopy, and flu shot.
Data: B. Mahato, Columbia University analysis of 2002 Medical Expenditure Panel Survey.

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Assumption 2

Racial and ethnic minorities are important litmus tests for the impact of a market-driven health care system because they are:

A. disproportionately uninsured
B. disproportionately low income
C. higher incidence of chronic health conditions

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What does race, ethnicity and language reveal?

"It's a baby. Federal regulations prohibit our mentioning its race, age, or gender."

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Assumption 3

Health disparities are important measures of inequalities in income, wealth, and power, both in the health care system and in the larger society

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Assumption 4

Health care reform has tended to focus on access issues requiring new funds to address unmet needs and quality issues that are addressed through financial incentives in a competitive marketplace (e.g. Pay-for-Performance)

Growth in health spending continues to exceed rate of growth in wages and inflation leading to fiscal crisis and growing uninsured

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Health Disparities are Key to Public Accountability in Fragmented Health Care Marketplace

- Health disparities invite civil rights principles of nondiscrimination
- Health disparities expose social determinants of health
- Health disparities provide basis for overcoming fragmentation in health care delivery at community level

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Title VI can address both “INTENTIONAL DISCRIMINATION” AND “DISPARATE IMPACT”

- Standards developed from laws into regulations (“CRITERIA OR METHODS OF ADMINISTRATION WHICH HAVE THE EFFECT OF SUBJECTING INDIVIDUALS TO DISCRIMINATION BECAUSE OF THEIR RACE, ETHNICITY, OR NATIONAL ORIGIN”)
- Process of enforcement (VOLUNTARY; OCR DECOUPLED FROM HEALTH CARE FINANCING)
- Courts have blocked the right to sue or PRIVATE RIGHT OF ACTION against government agency or business (Sandoval, 2001)
- Courts reluctant to challenge “business necessity” defenses (“HOSPITAL FLIGHT” cases)

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ADA bells and whistles to extend Title VI nondiscrimination standards to persons with disabilities

- **REASONABLE ACCOMMODATIONS** (required to ensure EQUALITY even if it COST MORE, unless it constitutes an UNDUE BURDEN or FUNDAMENTALLY ALTERS the organization)

- **PUBLIC ACCOMMODATION** (ALL BUSINESSES WHETHER PUBLICLY FUNDED OR NOT)

- **PROGRAM ACCESSIBILITY** (standards apply to program AS A WHOLE rather than to each entity within it

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Non-discrimination principles to ensure equal access for, and prohibit discrimination against, people with disabilities

1. SELF-DETERMINATION (who knows own needs)
2. NO "ONE SIZE FITS ALL" (people with disabilities have different needs)
3. EQUAL OPPORTUNITY (equal to people without disabilities)
4. INCLUSION (in planning, training, evaluation, etc.)
5. INTEGRATION (integrated setting)
6. PHYSICAL ACCESS (without physical barriers)
7. EQUAL ACCESS (to all aspects of the service)
8. EFFECTIVE COMMUNICATION (based on individual's needs)
9. PROGRAM MODIFICATION (via rules, policies, practices, procedures)
10. NO CHARGE for reasonable accommodations

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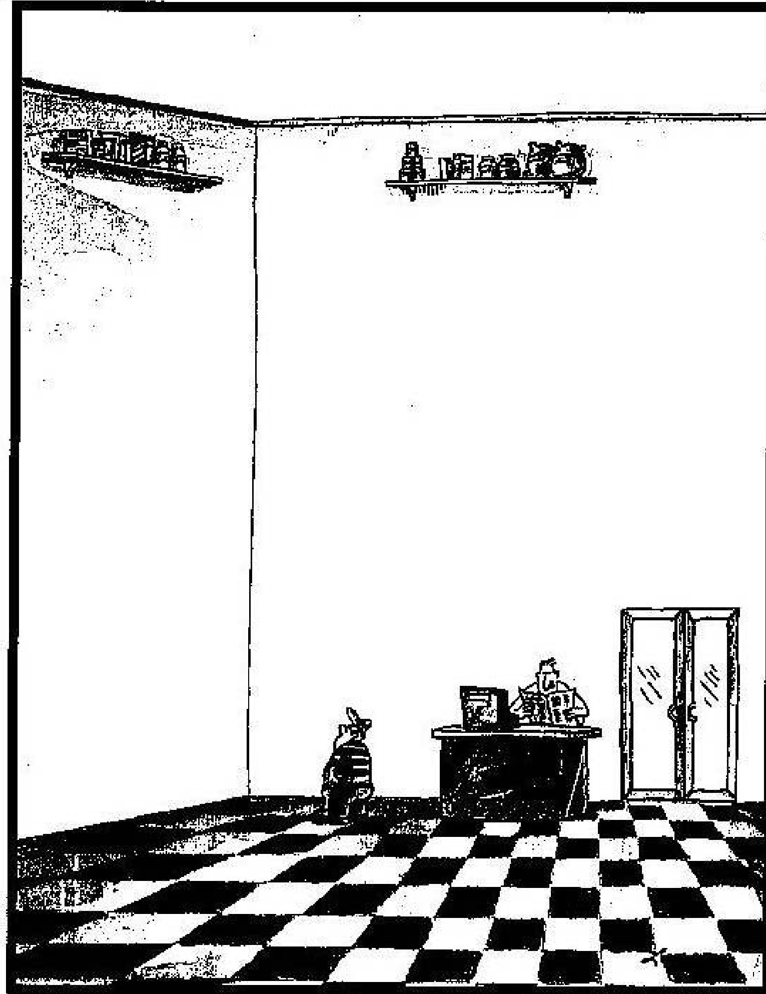
ADA Principles can be applied to health care delivery



Inconvenience stores

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Examples from ADA case law

- Oregon Medicaid prioritization process (1991-92)
- Risk adjusted utilization review (Zamora case in Medicare managed care in Texas, 1998)
- Hospital closing (Rancho Los Amigos Rehabilitation Center in Los Angeles in 2005)
- Evidence of direct threat for treating HIV patient in Maine dentist office (Bragdon v. Abbott, 1998)
- Accessibility standards for DME in physician offices (Metzler, et.al, v. Kaiser in CA, 2001)
- Access to “bilingual” mental health counselors who know sign language for deaf patients (Tugg v. Towey in FL, 1994)

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Limitations of applying civil rights laws

- Complaints depend on patient's knowledge of their rights and providers awareness of their obligations to avoid discrimination
- Courts reluctant to challenge business necessity defense
- Courts have blocked right to sue in disparate impact cases
- Title VI standards not sufficiently operationalized
- Racial and ethnic data not required to be collected in standardized way to enforce Title VI

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Incorporate nondiscrimination principles into health care regulations

- **Licensing** (e.g. accessibility requirements for breast cancer screening clinics in Mass., and data collection requirements for hospitals in Boston and Mass, statewide)
- **Quality assurance** (e.g. are waiting times and outcome measures comparable for all patient groups?)
- **Accreditation** (e.g. CLAS standards)
  - Consider proportional representation of minorities in health professions
- **Conditions of participation** (e.g. CON and community benefits under Hill-Burton)

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14 Culturally and Linguistically Appropriate Services (CLAS)

- **Cultural competency standards**
  - Definition of CLAS
  - Workforce diversity in health care professions
  - Staff CLAS training
- **Language access standards**
  - Interpreter services
  - Notice of right to interpreters
  - Qualified interpreters
  - Translation of materials
- **Organizational support**
  - Organizational framework
  - Performance monitoring
  - Data collection and analysis by race, ethnicity and language
  - Community needs assessment
  - Community partnerships
  - Grievance policy and procedures
  - CLAS communication strategy

Source:DHHS, Office of Minority Health, NATIONAL STANDARDS FOR CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES IN HEALTH CARE, March 2001

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How to institutionalize at community level?

- Role for local health department
  - Monitoring health disparities
  - Coordinating consensus building process for addressing health disparities in most efficient, effective, and equitable way
- Role of the state
  - Utilizing its regulatory authority
- Certificate of Need (CON) process

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R.U. Syrius Karlos Barney

"It's a little deal my HMO worked out with the airport to cut costs."

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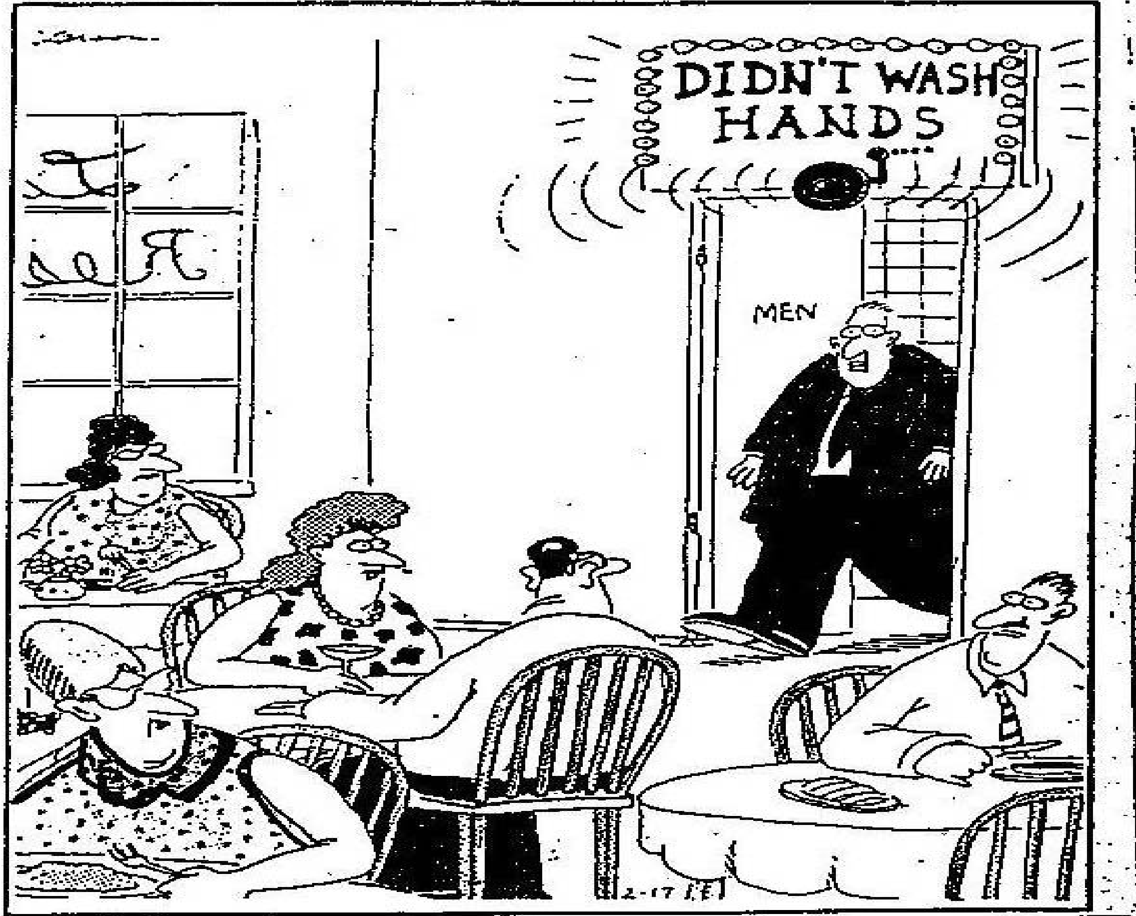

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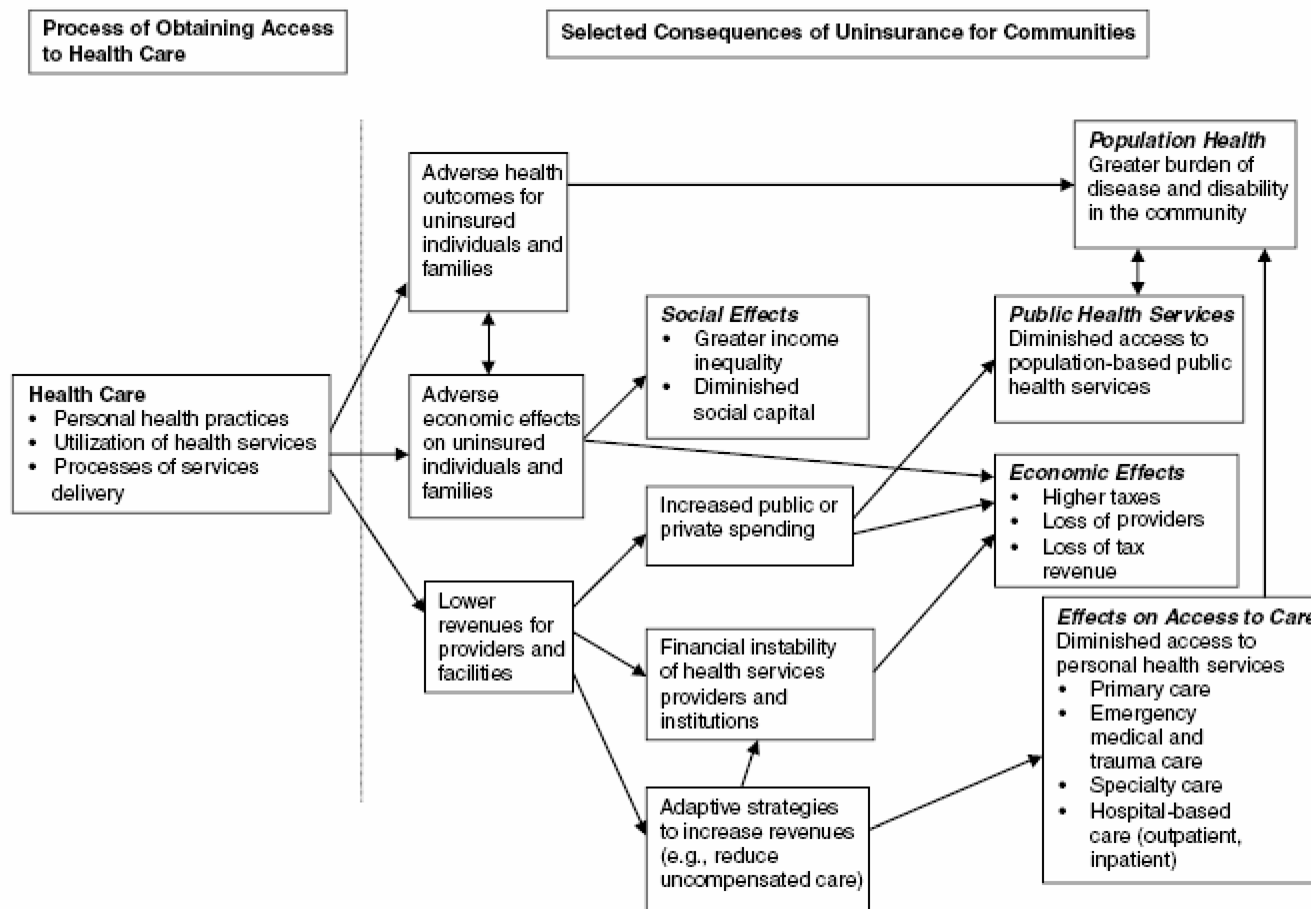

FIGURE ES.2 A conceptual framework for community effects.

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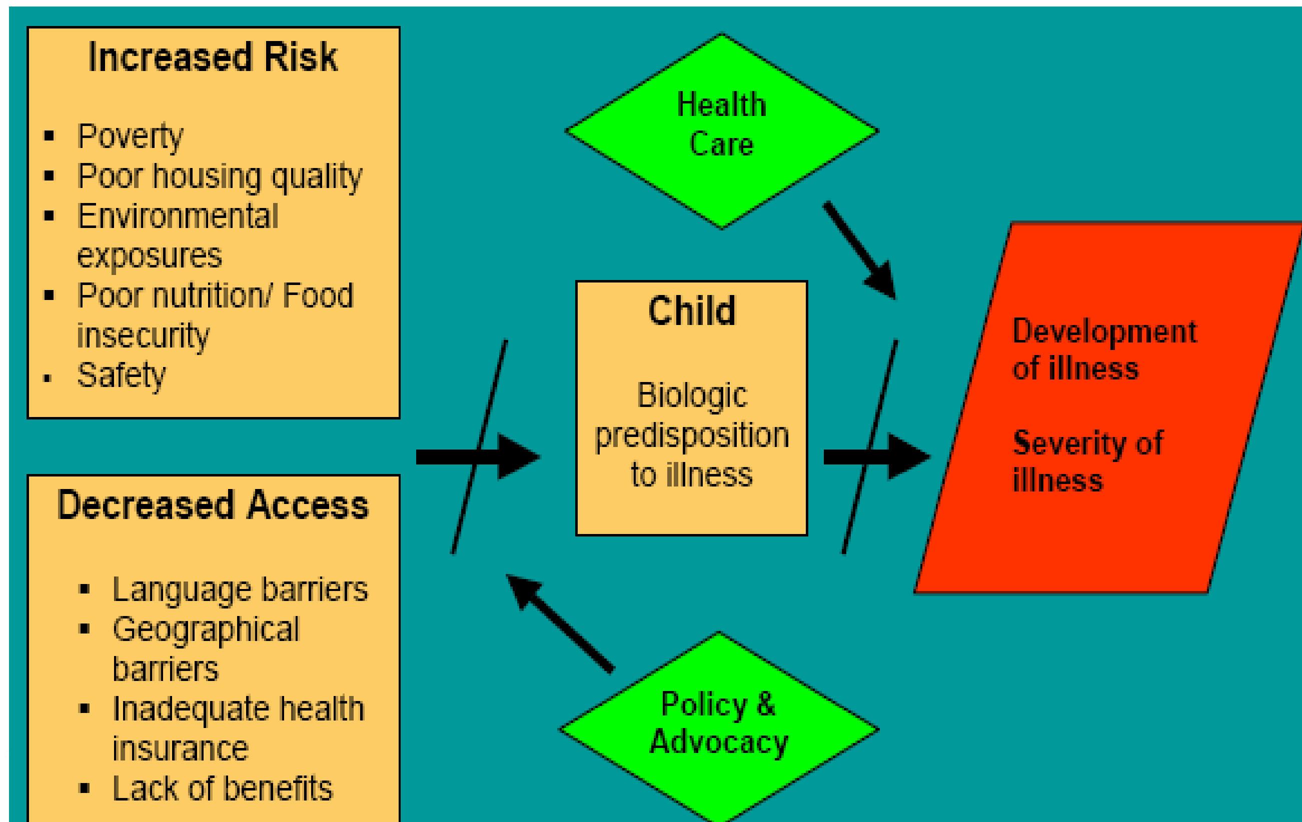

Source: Lauren Smith, The Medical Legal Partnership for Children, Boston University School of Medicine, from presentation "Eliminating Health Disparities: From Patients to Policy", 2006

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How nondiscrimination standards have been used as a basis for public accountability in non-health care sectors

- **Education**: No Child Left Behind (e.g. standardized test scores by grade level, race and disability to assess performance of school and school district)
- **Environmental Justice** (e.g. Executive Order #12898 to collect data on disproportionately high adverse environmental and health impacts on minority and low income communities with implications for permits, rule-making, or enforcement)
- **Cultural diversity in mass media** (e.g. FCC restrictions on consolidation in ownership to maximize local programming)
- **Housing mortgages** (e.g. Home Mortgage Disclosure Act requires reporting on home loan applicant's race and ethnicity to Federal Financial Institutions Examination Council)
- **Employment** (EEO monitoring of employment income by race, ethnicity, and gender by geographical area)

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Summary

- **Title VI is strongest part of Civil Rights Act of 1964** (based on federal spending power)

- **UNIVERSAL DESIGN**

- **By making health care delivery system function more efficiently, effectively, and equitably AS A SYSTEM at the community level**

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Summary

- **Title VI is strongest part of Civil Rights Act of 1964** (based on federal spending power)
  - 60% of total health care expenditures are public dollars
  - 100% of hospitals receive Medicare funding
  - 85% of physicians receive some Medicaid funding

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Summary

Acid test for civil rights is not how to empower individual patients to force a particular provider to eliminate barriers to equal access for racial and ethnic minorities, but how to distribute all health care resources within a geographical area in most efficient, effective, and equitable way (**UNIVERSAL DESIGN**)

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Summary

By making health care delivery system function more efficiently, effectively, and equitably AS A SYSTEM at the community level, this should:

A. OVERCOME FRAGMENTATION

B. GENERATE SAVINGS THAT CAN BE CAPTURED AND REDIRECTED TO SOCIAL DETERMINANTS OF HEALTH INCLUDING CLINICAL INTERVENTIONS

C. CREATE INCENTIVES FOR REDUCING INEQUALITIES IN OTHER SECTORS OF AMERICAN SOCIETY THAT CONTRIBUTE TO HEALTH DISPARITIES

D. SERVE AS A COUNTERVAILING INFLUENCE ON MARKET FORCES

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