

The Importance of Transparency and Patient Empowerment:

Eighth Annual Conference
on Healthcare Transparency & Patient
Advocacy

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Lexington, KY

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10 Essential Health Benefits of ACA

1. Inpatient hospital care
2. Outpatient care
3. Emergency room care
4. Maternity and newborn care
5. Mental health services
6. Prescription drugs
7. Rehabilitative services and devices
8. Laboratory services
9. Preventive services
10. Pediatric services

Vision for the Future

- Increase public awareness of early effective diagnosis and Rx
- Ensure supply of health services & providers.
 - Parity in the way we provide services
 - Community-based approaches
 - Culturally-competent, patient-centered physicians
 - Facilitate entry into Rx early
 - Reduce financial barriers to Rx
- Tailor Rx to age, gender, race and culture



If we do not change our direction,

we are likely to end up where we are headed.

●Ancient Chinese Proverb

Our Healthcare System Is at a Crossroads:

- Health Care is biggest item in budget (>3T)
- 318 M people, 13.7% w/o health insurance (Ages 18-64)
- 782 K doctors, 16,813 entering medical school
- Prescription drugs ↑ from 3B in 1960 – 262B in 2010
- < solo practitioners, > managed care HMOs, PPOs, IPAs
- Inadequate preventive health care & medical education
- Disparities in quality - system, provider, patient
- Cutting edge: drs, nurses, hospitals, academics, res.
- Burden of disease shift from acute (25%)/chronic (75%)

What Is Transparency in Health Care?

Healthcare transparency has been defined by the Institute of Medicine (IOM) as making available to the public, in a reliable and understandable manner, information on the health care system's quality, efficiency and consumer experience with care, which includes price and quality data, so as to influence the behavior of patients, providers, payers and others to achieve better outcomes (quality and cost of care).

What Is Patient Empowerment?

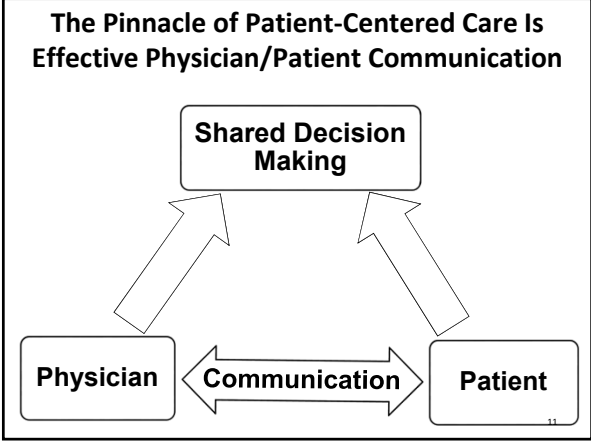
- Patient empowerment is the right of patients to take an active role in the decisions made about hers/his own health care.
- Patient empowerment requires a patient to take responsibility for aspects of care, such as:
 - ◆ respectful communications with one's doctors and other providers,
 - ◆ patient safety,
 - ◆ evidence gathering,
 - ◆ smart consumerism (making care cost decisions in the US),
 - ◆ shared decision-making and more.

Factors Affecting Our Health

- Poverty
 - What are the effects of poverty?
 - Lack of Health Care, Education, Housing, Food
 - Crime, Stress in children & adults, Poor environment
- Lack of education
 - How do we reach people for education?
 - Home, TV, Books, Online, Schools & Colleges, Churches
- Risky behaviors
 - How you live life more critical to longevity than genetics
 - Tobacco use, Alcohol & drug abuse, Car crashes, Obesity
- Access to health care
 - Provider, Financial, Cultural, Transportation, Time


Patient Rights

- Treatment that is safe and effective
- Physician that is
 - Competent
 - Caring
 - Trustworthy
- Right to be informed and give consent





Healthcare System presently is:

**physician-centered
not patient-centered**



Time Lapse from Lab to Practice

- Long delay in diffusion of medical knowledge.
- 17 years from clinical trials to standard practice.

Our Medical Systems Are Best Suited to Diseases of the Past
Not Those of the Present or Future

NEJM June 21, 2012 p. 2333 Vol 366

Healthcare Workforce

- The largest healthcare workforce is patients.

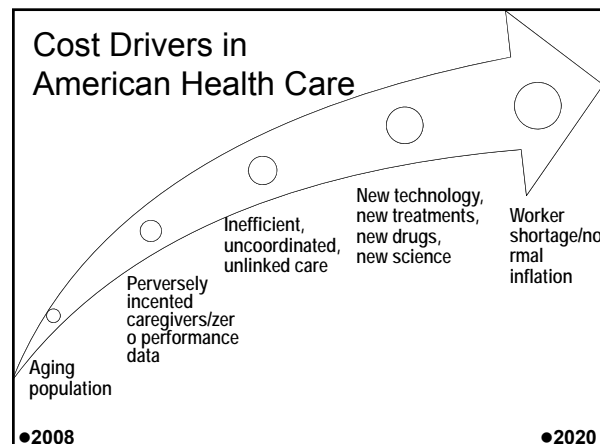
In 2000 we have:	In 2020 will need:
■ 782,000 Physicians	■ > 1 Million Physicians
■ 2 Million RNs	■ 2.8 M RNs
■ 600,000 LPNs	■ 0.9 M LPNs
■ 1.5 M Nurse's Aids	■ 2.3 M Nurse's Aids

We Are a Health Illiterate Society

- People cannot learn if they are not healthy and they cannot stay healthy if they are not educated.
- Teach good health to children in schools, on TV, online & books to children and adults.
- Present science-based answers rather than the present ubiquitous myths.
- Protect people by arming them with correct information.

Top Ethical Issues in Health Care

- Improving access to care
- Balancing care quality and efficiency
balancing quality and safety with efficiency
- Building and sustaining the healthcare workforce of the future
- Addressing end-of-life issues
- Allocating limited resources – meds & – shortage of donor organs
- Communication policies – e-records, pt. privacy



Reasons for Increased Cost of Health Care

- Increasing number of elderly – living longer
- Greater burden of chronic disease
- More medications used
- Improved technology
- Higher rates of hospitalizations
- Increased use of nursing facilities
- ADL need for 40% for >age 85

High Cost Is not Correlated with:

- Higher quality
- More access
- Better outcomes Higher satisfaction
- Reduced mortality
- Improved access to care

Hospitals



Adverse Events and Complications from Hospitalizations

- Post-operative venous thromboembolic events <1/1000
- Post-operative hip fracture <0.3/1000
- Events associated with central venous catheters 2/1000
- Iatrogenic pneumothorax 0.9/1000
- Hospital-acquired infections in ICU 4.8-11/1000
- Inappropriate use of medications in elderly

Principles of Value-based Competition

- Focus on value for patients, not just lowering cost
- Competition based on results
- Competition centered on medical conditions over full cycle of care
- High quality care should be less costly
- Value driven by provider experience, scale and learning at the medical condition level.
- Competition regional and national, not just local
- Results to support VBC must be widely available
- Innovations that increase value must be strongly rewarded.

Characteristics of Quality and Safety from Patients' Perspective

- Respect for the patient's values, preferences
- Coordinated and integrated care
- Clear high quality information and education for patient and family
- Physical comfort including pain management
- Emotional support and alleviation of fears and anxiety
- Involvement of family and friends as appropriate
- Continuity
- Access to care

Health Literacy: Making Your Doctor's Visits More Meaningful

- Take a trusted person with you.
- Ask questions if you don't understand something.
- Bring all your medications with you.
- Write down question and concerns before you go.
- Ask your doctor to write down information and instructions discussed.
- Make sure to tell your doctors if you vision and hearing problems.

Recommendations for the New Healthcare System

- Healthy people in healthy communities
- Healthcare system that is accessible, available and affordable
- Prevention-focused, purpose-driven and solution-oriented
- Individual responsibility and involved in care
- Healthcare professionals who are patient-centered

Role of Healthcare Providers: Advocacy

Listen, Learn and Lead

- A – Aware, Advocacy, Action plan
- D – Delivery of pt.-centered health care, Diversity
- V – Value, Voice and Vision
- O – Outcome measures, Open doors
- C – Competent, 5 Cs of leadership Clarity of vision, Competent, Consistent, Commitment & Control
- A – Assessment, educate, empowerment
- C – Competent
- Y - You are your own best advocate! Science-based medicine

THE END

●EXTRA SLIDES

8 Tests to Save Your Life

- Height, weight – BMI
- BP
- Mammogram
- PAP or PSA
- Lipid profile
- Hgb A₁C, HIV
- ECHO, EKG
- Colonoscopy

7 Characteristics of Healthy People

- Eat breakfast - 3 meals & 3 snacks
- High fiber, low saturated fat diet
- Exercise 20-30 minutes
- 7 - 8 hours sleep
- Don't smoke
- Drink only in moderation
- Practice safe sex

Vision for the 21st Century

- Healthy People in Healthy Communities
- Design & develop a consumer responsive healthcare system for all ages.
- Healthcare system that is available, affordable, accessible
- Patient-centered, prevention-focused, purpose-driven, solution-oriented
- Fosters individual responsibility, human dignity; improves health status and enhances quality of life

Strategies

- Educational strategies
- Access strategies
- Prevention strategies
- Intervention strategies
- Strategies of compassion
- Research strategies
- Political strategies
- Leadership strategies

5 C's of Leadership – Clarity of vision, Consistency, Competency, Commitment, Control

30 Safe Practices for Better Health Care

- Agency for Healthcare Research & Quality and the National Healthcare Forum have developed “30 Safe Practices for Better Health Care”

Tackling Rising Healthcare Costs

- Medicare for all to achieve universal coverage
- Control rising healthcare costs
- Healthcare systems engineering
- Establish a health policy commission
- Enhance transparency
- Address medical malpractice
- Establish eHealth Charts, HIT
- Establish wellness and prevention programs

• NEJM, Vol. 366, p. 785 August 2012

Things You Need to Know

- High administrative costs are rising
 - 25% of hospital expenditures on administration
 - 30% of all healthcare spending
- High cost, low or variable quality, too many preventable errors in doctoring and medicine
- Restrictions on choice
- Rationing of Limited access
- Raft of costly lawsuits

What Does the Health System Reform Mean to You?

- Ins. Claims processing standardized & streamlined, lowering Dr.'s costs and improving practice revenue cycles.
- Medicare Part D donut hole will be closed.
- Clinical comparative effectiveness research will be promoted, but cannot be used to dictate treatment decisions or coverage.
- Prevention and wellness initiatives will be promoted.
- Funding is provided to test medical liability reforms, such as health courts and disclosure laws.
- And, primary care payment for Medicaid must be the same as it is for Medicare, with the federal government covering that cost for the first 4 years.

AMA

What Does the Health System Reform Mean to You?

- 32 M uninsured Americans will gain access to health ins.
- Insurers cannot deny patients based on pre-existing conditions.
- No lifetime caps on coverage or threats of cancellation
- Children permitted to remain on parents' policies until age 26.
- Competition will be introduced into the ins. marketplace.
- Health insurance exchanges & co-ops created for pooling of coverage for individuals & small businesses.
- Tax credits to small businesses for purchase of health ins.
- High-risk insurance pools will be created.
- Subsidies to help low-income individ. & families purchase ins.

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Vision for the Future

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Health of Older African Americans

- Greater morbidity & mortality at every point in lifespan
- Heart disease & cancer leading causes of death
- HTN affects 1 of 3 A-A, 60% greater risk for death & disability from stroke & CAD
- CVD is 80% higher for AA women
- Cancer incidence rates 10% higher
- IMR 2.5 times higher
- LER is lower
- Women 2X greater risk of dying HCVD
- Cancer mortality is 20-40% higher

Obesity – An Epidemic

- Overweight and obesity has reached epidemic proportions in the United States, as well as worldwide.(3)
- Roughly 31% of American adults meet the criterion for obesity - about 59 M American adults.
- More than 67% of the US adult population have a BMI ≥ 25 kg/m² putting them in the overweight category. (4)
- In an effort to increase public awareness of the epidemic proportion of obesity, the Surgeon General has issued a call to action to prevent and treat overweight and obesity and their associated health complications.(5)

3. World Health Organization, (1996) Obesity: Preventing and managing the global epidemic, Report of WHO Consultation on Obesity, Geneva, 3-5 June, 1997, WHO, 1998.

4. National Center for Health Statistics (1999) (2007) Prevalence of overweight and obesity among adults.

5. US Department of Health and Human Services. The Surgeon General's call to action to prevent and decrease overweight and obesity. (Rockville, MD) US Department of Health and Human Services, Public Health Service, Office of the Surgeon General (2001).

National Center for Health Statistics http://www.obesity.org/information/what_is_obesity.asp, Accessed on May 4, 2009

Old Ibo Saying

**Not to know is bad.
 Not to want to know is worse.
 Not to hope is unthinkable.
 But not to care is absolutely unforgivable**

Recommendations for Improving the Healthcare System

- Equitable care for all
- Universal health insurance:
 - W/o pre-existing conditions, caps
 - Parity for physical & mental conditions
 - Gender equity
 - W/o high deductibles and co-pays
 - Promote a diverse workforce
- Provide long-term care for disabled & elderly
- Data collection
- Health information technology (HIT)
- Electronic medical records

Population Data

In 2012:

- World population – Apr. 7 Billion
- US population 311 M
 - Children 74 M
 - Seniors 40 M
 - Hispanics 50 M
 - African Americans >40 M
 - Prison 2.3 M

(<http://www.census.gov/population/www/popclockus.html> on Sept 13, 2011)

Ethnic Diversity of the US Population

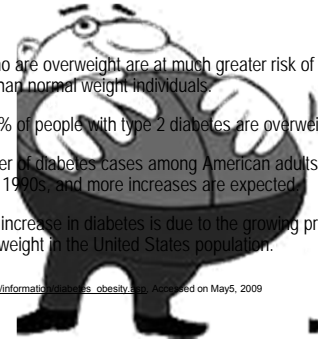
- European American 63%
- African American 13.5%
- Hispanic 15%
- Asian/Pacific Is. 5%
- Native American <1%
- More than 1 race 2.4%

US Dept of State Mar 30, 2009 and Human Mortality Data Base, 2010

Carrying extra body weight and body fat go hand and hand with the development of type 2 diabetes.

- People who are overweight are at much greater risk of developing type 2 diabetes than normal weight individuals.
- Almost 90% of people with type 2 diabetes are overweight.
- The number of diabetes cases among American adults jumped by a third during the 1990s, and more increases are expected.
- This rapid increase in diabetes is due to the growing prevalence of obesity and extra weight in the United States population.

<http://www.obesity.org/information/obesity/obesity.htm>, Accessed on May5, 2009



Prevalence of Mental Health Disorders

- 50% of all lifetime mental disorders begin by age 14.¹
- 75% begin by age 24.¹
- In 2004, almost ¼ of all stays in US community hospitals for patients age ≥18 (7.6 M of nearly 32 M stays) were for mental disorders:
 - Depression
 - Bipolar disorder
 - Schizophrenia
 - Substance abuse related disorders

1. Kessler, RC, et al. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. Arch Gen Psych, 62(6).
2. Agency for Healthcare Research and Quality. (2009). In National Healthcare Disparities Report, 2008. Rockville, MD: USDHHS.

Barriers to Access of Mental Health Care

- | | |
|--|---|
| <ul style="list-style-type: none"> ■ Provider/System Barriers <ul style="list-style-type: none"> – Stigma/discrimination – Cost/lack of health insurance or underinsured – Clinician bias – Lack of continuity of system | <ul style="list-style-type: none"> ■ Patient Barriers <ul style="list-style-type: none"> – Lack of information of where, how, when to seek help – Inability to navigate system – Lack of awareness of disorder – Help-seeking behavior – Mistrust/fear |
|--|---|

Barriers to Reducing Disparities in Health Care

- Cost/lack of health insurance/underinsured
 - Adults ages 19 – 29 are among the largest and fastest growing segment of the populations without health insurance in the US.¹
 - Uninsured individuals are:
 - about 6X as likely to lack a source of care
 - 4X as likely to be w/o a usual source of care for financial reasons.²
- Young people of color are disproportionately uninsured.²

1 Collins, SR. (2009, Apr 23). Young and vulnerable: The growing problem of uninsured young adults and how new policies can help. <http://commonwealthfund.org/Content/Publications/Testimonies/2009/Apr/Testimony-Young-and-Vulnerable.aspx>.

2. Agency for Healthcare Research and Quality. (2009). National Healthcare Disp Rep. 2008. USDHHS.

Cultural Contexts in Health Care

Healthcare System

- Accessibility & Location of Facilities
- Workforce Diversity
- Institutional Reputation within the Community (bias, discrimination, racism; community asset & advocate)
- History of Providing Care to Ethnic Populations
- Culturally & Linguistically Competent Workforce
- Health Disparities Research Portfolio
- Community Partnerships & Advocacy
- Accepted Insurance Plans (eg, Medicaid)

Dr. Robert Like, Depression Diagnosis and Treatment

What We Need to Do

- Continue to build a scientific base
- Overcome stigma
- Improve public awareness of effective treatment
- Ensure supply of mental health services and providers
- Ensure delivery of state of the art treatments
- Tailor treatment to age, gender, race and culture.
- Facilitate entry into treatment
- Reduce financial barriers to treatment

Strategies

- Educational strategies
- Access strategies
- Prevention strategies
- Intervention strategies
- Strategies of compassion
- Research strategies
- Political strategies
- Leadership strategies

Recommendations

- Universal health insurance
- Promote a diverse workforce
- Deliver patient-centered care
- Data collection
- Equitable care for all

What Is the Role of Transformational Leaders of the 21st Century?

- L - Learn, listen and lead
- E - Educate
- A - Aware, advocacy and action plan
- D - Determined boldness
- E - Empowerment
- R - Reach out, responsible, risk
- S - Successful

THE END

Expense of Malpractice Premium, Lawsuits, etc. Are High

- 65B? /year on malpractice premiums by professionals. Multibillions by hospitals, nursing home. Threat of malpractice suits – defensive medicine with unnecessary tests, over-diagnosis and redundant or unnecessary treatment.

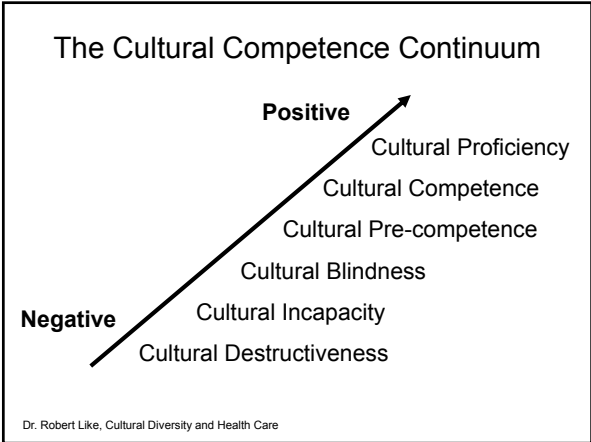
Major Problems of Current US Healthcare System - ACA

- Access**
 - M's no health insurance (40 M adults)
 - 1/2 < 35 years old, 3/4 income <\$40K
- Cost**
 - Costs too much, delivers too little
- Quality**
 - Gross lapses in quality of care
 - Major health disparities
 - Lack of transparency
 - Value = Outcomes/Cost (VBHC)

What Does the ACA Mean to You?

- Millions of uninsured citizens gain access to health ins.
- Cannot deny patients based on pre-existing conditions.
- No lifetime caps on coverage or threats of cancellation
- Prevention and wellness are promoted
- Children may remain on parents' policies 'til age 26.
- Competition introduced into the insurance marketplace.
- Tax credits to small businesses for health ins.
- High-risk insurance pools will be created.
- Subsidies to help low-income persons purchase ins.

AMA



Disparities in Quality of Health Care

- Problems related to provider**
 - Language, cultural differences, religious, mistrust of western medicine, familial & hierarchical roles
- Problems related to the system**
 - Location, time blocks, appropriateness of material
- Problems related to the patient**
 - Education, socioeconomic status, cultural competency

Myths

- Pregnancy prevention is primarily women’s responsibility
- Sexual pleasure is irrelevant to women
- Gender neutral, “Right to Sexual Pleasure”
- Pleasure-seeking behavior
- Condom use and innovations
- Campaigns on lengthening pleasure
- Pleasure in relation to gender and power
- Role of pleasure seeking on reproductive & sexual health

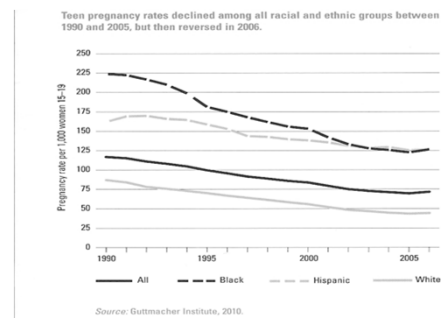
Major Determinants of Health

- **Social and behavioral factors** 50%
- **Environment** 20%
- **Genetics** 20%
- **Access to care** 10%

Our Healthcare System Is at a Crossroads, cont.:

- Greater focus on value (healthcare outcomes/\$)
- Inadequate preventive health care
- Wide disparities in health care
- Best doctors, nurses, hospital & academic health centers, cutting-edge research
- Population growing older and more diverse
- Burden of disease shifting from acute to chronic
- Physician-centered → Patient-centered
- Physician : Competent, Trustworthy and Caring

Distressing Trends in Teen Pregnancy Rates



America’s Health Check-up

- >311 million population
- >39 million > 65 yrs
- 51 million without health insurance
- 67% overweight or obese
- 8% Diabetes Mellitus
- 27% high BP
- 40% little exercise
- 83% do not eat 5 fruits and vegetables/day

Sexual & Reproductive Health of Persons Aged 10-24 Years

- Many young person engage in sexual risk behaviors & experience negative outcomes.
- 745,000 pregnancies in females <20 yrs. Of age
- 22,000 adolescents living with HIV/AIDS
- >19 M living with STIs, ½ < 24 yrs. of age.
- Risk increases with age.
- In ages, 10-14 years
 - 16,000 pregnancies
 - 18,000 STIs
 - 27,000 sexual assaults

Burden of Disease

- Sexual and reproductive health problems account for:
 - 18% of the total global burden fo disease and
 - 32% of the burden among women of reproductive age.

Some Statistics

- In the US, mental disorders account for 15% of the overall burden of disease from all causes, higher than cancer.
- Mental health and mental illness affect more than 1/5 of all Americans.
- Treatment is available for many of these disorders.

Sexual & Reproductive Health of Persons Aged 10-24 Yrs., Cont.

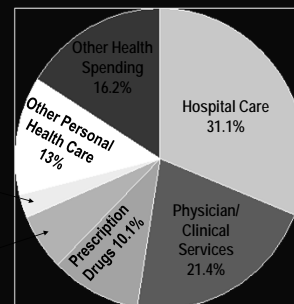
- Chlamydia, Gonorrhea & Syphilis are highest in southern states and in AA.
- Birth rate for teens declined from 1991-2005, but increase past 2 years.
- HIV/AIDs in young males aged 15-19 doubled in past 10 years.
- Noticeable disparities exist
 - Pregnancy rate for AA is 2.4 times higher
 - HIV/AIDS rate for AA is 4.96/100,000 vs. 2.5/100,000 for European Americans

America Is Not a Sexually Health Nation as Manifested by:

- More than 1B acts of unprotected sex among single adults
- 65 M live with an incurable STI.
- 19 M STIs, 1/2 < 24 yrs.
- >745,000 unintended teen pregnancies
- 6 M pregnancies, 3.9 M births, 1.3 M abortions
- >1.1M living with HIV
- > 56,000 new cases of HIV diagnosed ea. yr.
- Despite proven effectiveness of latex condoms & microbicides, single, sexually active Americans ages 18-54 use them only about 25% of the time.

Fertility increase vs. Contraception

Distribution of National Health Expenditures by Type of Service, 2007



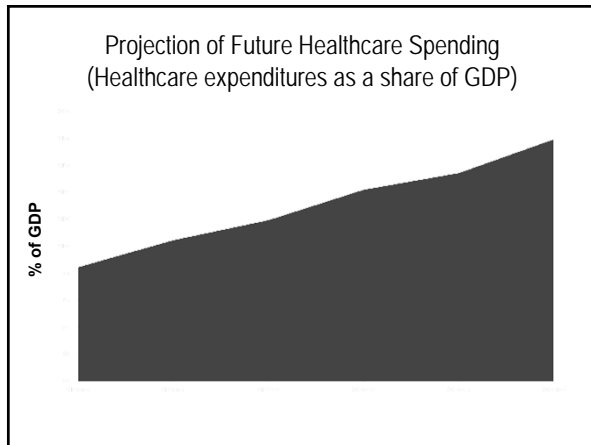
WHO Analysis of the World's Health Systems

Criterion for Analysis	Ranking of the US
Overall level of population health	# 1 in spending 17.9 percent of its gross domestic product
Health disparities within a population	# 37 out of 151 countries according to its performance
Health system's responsiveness to needs of the population	# 54 in its fairness (WHO, 2000)
Distribution of responsiveness (Rich v. Poor/ Goodness v. Fairness)	# 72 in its performance on health level
Distribution of financial burden. (Who pays?)	

"Here Are 2 Truisms"

- Rich countries have better health than poor countries, and
- Medical care improves health.

Marmot and Bell, JAMA Vol. 301, No. 11, Mar 18, 2009



To Achieve Universal Coverage:

- Medicare for all
- Medicaid
- Subsidies
- Exchanges
- Mandatory

Children in the US

- 74 million children live in the United States:
- 1.3% are American Indian/Alaska Native, non-Hispanic
- Almost 2 million are two or more races, non-Hispanic
- 4.4% are Asian/Pacific Islander, non-Hispanic
- 15.2% are Black, non-Hispanic
- 21.8% are Hispanic
- 56.2% are White, non-Hispanic

Source: Children's Defense Fund Compiled Nov. 2008

How America Ranks Among Industrialized Countries in Investing in and Protecting Children

- 1st in gross domestic product
- 1st in number of billionaires
- 1st in number of persons incarcerated
- 1st in health expenditures
- 1st in military technology
- 1st in defense expenditures
- 1st in military weapons exports
- 21st in 15-year-olds' science scores
- 21st in low birth weight rates
- 25th in 15-year-olds math scores
- 28th in infant mortality rates
- Last in relative child poverty
- Last in the gap between the rich and the poor
- Last in adolescent birth rates (ages 15-19)
- Last in protecting our children against gun violence

Children's Defense Fund

If we compare just black child well-being in America to child well-being in other nations, according to UNICEF:

- 66 nations have lower infant mortality rates including Sri Lanka.
- Over 100 nations have a lower incidence of low birth weight, including Algeria, Botswana and Panama.
- Black women in the US are more likely to die from complications of pregnancy or childbirth than women in Uzbekistan.