Systems of Power | Axes of Inequity

Parallels
Intersections
Braiding the strands

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Keynote Address
Health Disparities Research at the Intersection of Race, Ethnicity, and Disability
A National Conference
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Levels of health intervention

Jones CP et al. *J Health Care Poor Underserved* 2009.
Jones CP et al. *J Health Care Poor Underserved* 2009.
Jones CP et al. *J Health Care Poor Underserved* 2009.
Jones CP et al. *J Health Care Poor Underserved* 2009.
Jones CP et al. *J Health Care Poor Underserved* 2009.
Addressing the social determinants of health

Primary prevention

Safety net programs and secondary prevention

Medical care and tertiary prevention
But how do disparities arise?

- Differences in the quality of care received within the health care system

- Differences in access to health care, including preventive and curative services

- Differences in life opportunities, exposures, and stresses that result in differences in underlying health status


Jones CP et al. *J Health Care Poor Underserved* 2009.
Jones CP et al. *J Health Care Poor Underserved* 2009.
Differences in quality of care
(ambulance slow or goes the wrong way)

Jones CP et al. *J Health Care Poor Underserved* 2009.
Addressing the social determinants of equity:

Why are there differences in resources along the cliff face?

Why are there differences in who is found at different parts of the cliff?

Jones CP et al. *J Health Care Poor Underserved* 2009.
3 dimensions of health intervention
3 dimensions of health intervention

Health services
3 dimensions of health intervention

Health services

Addressing social determinants of health

Jones CP et al. *J Health Care Poor Underserved* 2009.
3 dimensions of health intervention

Health services

Addressing social determinants of health

Addressing social determinants of equity

Jones CP et al. *J Health Care Poor Underserved* 2009.
Healthy People 2020
www.healthy_people.gov

Disability and Health
- 20 objectives
DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

DH-6: Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.

DH-7: Reduce the proportion of older adults with disabilities who use inappropriate medications.

Healthy People 2020
Disability and Health
DH-2: Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

DH-4: Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers.

DH-19: Reduce the proportion of people with disabilities who experience nonfatal unintentional injuries that require medical care.

DH-20: Increase the proportion of children with disabilities, birth through age 2 years, who receive early intervention services in home or community-based settings.
DH-8: Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs.

DH-9: Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities.

DH-10: Reduce the proportion of people with disabilities who report barriers to obtaining the assistive devices, service animals, technology services, and accessible technologies that they need.

DH-13: Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish.

DH-17: Increase the proportion of adults with disabilities who report sufficient social and emotional support.

DH-18: Reduce the proportion of people with disabilities who report serious psychological distress.

Healthy People 2020
Disability and Health
**DH-11:** Increase the proportion of newly constructed and retrofitted U.S. homes and residential buildings that have visitable features.

**DH-12:** Reduce the number of people with disabilities living in congregate care residences.

**DH-14:** Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

**DH-15:** Reduce unemployment among people with disabilities.

**DH-16:** Increase employment among people with disabilities.

*Healthy People 2020*

*Disability and Health*
**DH-1:** Include in the core of Healthy People 2020 population data systems a standardized set of questions that identify “people with disabilities.”

**DH-3:** Increase the proportion of U.S. master of public health (M.P.H.) programs that offer graduate-level courses in disability and health.
What is racism?

A system

What is racism?

A system of structuring opportunity and assigning value

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A system of structuring opportunity and assigning value based on the social interpretation of how we look (which is what we call “race”), that

- Unfairly disadvantages some individuals and communities
- Unfairly advantages other individuals and communities
- Saps the strength of the whole society through the waste of human resources

What is *inequity*?

A system of structuring opportunity and assigning value based on *[fill in the blank]*
What is [inequity]?

A system of structuring opportunity and assigning value based on [fill in the blank], that

- Unfairly disadvantages some individuals and communities
- Unfairly advantages other individuals and communities
- Saps the strength of the whole society through the waste of human resources
Many possible axes of inequity

- “Race”
- Gender
- Ethnicity
- Disability status
- Labor roles and social class markers
- Nationality, language, and legal status
- Sexual orientation
- Geography
- Religion

These are risk markers (as opposed to risk factors)
Levels of Racism

- Institutionalized
- Personally-mediated
- Internalized

Institutionalized racism

- Differential access to the goods, services, and opportunities of society, by “race”

- **Examples**
  - Housing, education, employment, income
  - Medical facilities
  - Clean environment
  - Information, resources, voice

- **Explains the association between social class and “race”**

Personally-mediated racism

- Differential assumptions about the abilities, motives, and intents of others, by “race”
- Differential actions based on those assumptions

- Prejudice and discrimination

- Examples
  - Police brutality
  - Physician disrespect
  - Shopkeeper vigilance
  - Waiter indifference
  - Teacher devaluation

Internalized racism

- Acceptance by the stigmatized “races” of negative messages about our own abilities and intrinsic worth

- **Examples**
  - Self-devaluation
  - White man’s ice is colder
  - Resignation, helplessness, hopelessness

- Accepting limitations to our full humanity

Levels of Racism: A Gardener's Tale

Who is the gardener?

- Power to decide
- Power to act
- Control of resources

Dangerous when
- Allied with one group
- Not concerned with equity

Measuring institutionalized racism

- **Scan for evidence of “racial” disparities**
  - “Could racism be operating here?”
  - Routinely monitor opportunities as well as outcomes by “race”

- **Identify mechanisms**
  - “How is racism operating here?”
  - **Structures**: the who?, what?, when?, and where? of decision-making
  - **Policies**: the written how?
  - **Practices and norms**: the unwritten how?
  - **Values**: the why?
Achieving health equity

“Health equity” is assurance of the conditions for optimal health for all people

Achieving health equity requires
- Valuing all individuals and populations equally
- Recognizing and rectifying historical injustices
- Providing resources according to need

Health disparities will be eliminated when health equity is achieved

Jones CP 2010, adapted from the National Partnership for Action to End Health Disparities.
Musings

- “Race”
  - Group attribute
  - Deemed immutable
  - Assumptions made about value
  - Structural barriers sometimes invisible and ignored

- Disability status
  - Individual attribute
  - Recognized that status can change
  - Assumptions made about value
  - Structural barriers often visible but still ignored
Musings

- Dependence versus independence
- Identity versus condition
- Salience of advocacy
- Visibility versus invisibility (abilities, barriers)
- Social construction (interaction with environment)
- Mechanisms of accommodation
- Role of segregation
- Universal human rights versus “minority” or “underserved” status
Musings

- Difficult to recognize systems of inequity that advantage oneself
- Especially difficult when disadvantaged by other systems of inequity

- Can examine which of multiple identities is more salient in a given setting
- Need avoid the game “Whose oppression is worse?”
Musings

- **Parallels: systems of inequity**
  - Structure opportunity
  - Assign value

- **Intersections: axes of inequity**
  - In individuals
  - In communities

- **Braiding the strands: convergent strength**
  - Expand advocacy agendas
  - Integrate research agendas
  - Share successful policy strategies
CRPD

- **Convention on the Rights of Persons with Disabilities**
  - International disability rights treaty adopted by the UN General Assembly in 2006

- US signed in 2009
- US has not yet ratified
ICERD

- *International Convention on the Elimination of all forms of Racial Discrimination*
  - International anti-racism treaty adopted by the UN General Assembly in 1965
  - [http://www2.ohchr.org/english/law/cerd.htm](http://www2.ohchr.org/english/law/cerd.htm)

- US signed in 1966
- US ratified in 1994
- 2nd US report submitted to the UN Committee on the Elimination of Racial Discrimination (CERD) in 2007
  - [http://www2.ohchr.org/english/bodies/cerd/docs/AdvanceVersion/cerd_c_usa6.doc](http://www2.ohchr.org/english/bodies/cerd/docs/AdvanceVersion/cerd_c_usa6.doc)
CERD Concluding Observations

- 14-page document (8 May 2008) available online
  http://www.state.gov/documents/organization/107361.pdf

- Concerns and recommendations
  - Racial profiling (para 14)
  - Residential segregation (para 16)
  - Disproportionate incarceration (para 20)
  - Differential access to health care (para 32)
  - Achievement gap in education (para 34)
Our goal: To expand the conversation

Health services
Our goal: To expand the conversation

Health services

Social determinants of health
Our goal: To expand the conversation

Health services

Social determinants of health

Social determinants of equity

Our tasks

- **Put racism on the agenda**
  - Name racism as a force determining the other social determinants of health
  - Routinely monitor for differential exposures and opportunities (as well as outcomes) by “race”

- **Put abilism on the agenda**
  - Name abilism as a force determining other social determinants of health
  - Routinely monitor for differential exposures and opportunities (as well as outcomes) by disability status
Our tasks

- Ask, "How is racism operating here?"
  - Identify mechanisms in structures, policies, practices, norms, and values
  - Attend to both what exists and what is lacking

- Ask, "How is abilism operating here?"
  - Identify mechanisms in structures, policies, practices, norms, and values
  - Attend to both what exists and what is lacking
Our tasks

- **Organize and strategize to act**
  - Join in grassroots organizing around the conditions of people's lives
  - Identify the structural factors creating and perpetuating those conditions
  - Link with similar efforts across the country and around the world
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Resources

- National Partnership for Action to End Health Disparities
  Office of Minority Health, US Department of Health and Human Services
  http://www.minorityhealth.hhs.gov/npa/
  - National Stakeholder Strategy for Achieving Health Equity
  - HHS Action Plan to Reduce Racial and Ethnic Health Disparities

Regional Health Equity Councils
http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=42#1
Resources

- **Healthy People 2020**

**Overarching goals:**
- Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death.
- Achieve health equity, eliminate disparities, and improve the health of all groups.
- Create social and physical environments that promote good health for all.
- Promote quality of life, healthy development, and healthy behaviors across all life stages.

42 topic areas, including 13 new ones
Resources

- **National Prevention Strategy**
  National Prevention, Health Promotion, and Public Health Council
Resources

- **US-Brazil Joint Action Plan to Eliminate Racial and Ethnic Discrimination and Promote Equality**

  Five-year bilateral agreement signed in 2008
  
  [http://www.state.gov/p/wha/rls/2008/111446.htm](http://www.state.gov/p/wha/rls/2008/111446.htm)
  [http://www.state.gov/p/wha/rt/social/brazil/index.htm](http://www.state.gov/p/wha/rt/social/brazil/index.htm)

**Areas of focus**

- Civil society engagement
- Economic opportunities and labor
- Education
- Environmental justice
- Health
- Justice
Resources

- CDC Racism and Health Workgroup
  rahw@cdc.gov

  Communications and Dissemination
  Education and Development
  Global Matters
  Liaison and Partnership
  Organizational Excellence
  Policy and Legislation
  Science and Publications
Resources

- *Race: The Power of an Illusion*
  California Newsreel
  http://www.pbs.org/race

- *RACE—Are We So Different?*
  American Anthropological Association
  http://www.understandingrace.org/home.html
Resources

- 3rd World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance
  Convened by the United Nations in Durban, South Africa in 2001
  http://www.un.org/WCAR/

  Durban Declaration and Programme of Action
Resources

- *Unnatural Causes: Is Inequality Making Us Sick?*
  California Newsreel
  http://www.unnaturalcauses.org

- *Closing the gap in a generation: Health equity through action on the social determinants of health*
  WHO Commission on Social Determinants of Health
Resources

- World Conference on Social Determinants of Health
  Convened by the World Health Organization in Rio de Janeiro, Brasil in 2011
  http://www.who.int/sdhconference/en/

  Rio Political Declaration on Social Determinants of Health
  http://www.who.int/sdhconference/declaration/en/
Resources

- *International Convention on the Elimination of all forms of Racial Discrimination (ICERD)*
  Adopted by the United Nations General Assembly in 1965
  [http://www2.ohchr.org/english/law/cerd.htm](http://www2.ohchr.org/english/law/cerd.htm)

- *Committee to Eliminate Racial Discrimination (CERD)*
  Office of the United Nations High Commissioner for Human Rights
  [http://www2.ohchr.org/english/bodies/cerd/](http://www2.ohchr.org/english/bodies/cerd/)
Resources

- 2007 USA State Department report to the CERD
  http://www2.ohchr.org/english/bodies/cerd/docs/AdvanceVersion/cerd_c_usa6.doc

- 2007 NGO shadow reports to the CERD
  http://www2.ohchr.org/english/bodies/cerd/cerds72-ngos-usa.htm

- 2008 CERD Concluding Observations to the USA
  http://www.state.gov/documents/organization/107361.pdf
Resources

- Report of the Secretary's Task Force on Black and Minority Health
  Margaret M. Heckler, Secretary
  U.S. Department of Health and Human Services

- Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care
  Brian D. Smedley, Adrienne Y. Stith, Alan R. Nelson, Editors
  Institute of Medicine of the National Academies
Resources

- *The Gardener’s Tale* podcast
  CityMatCH Health Equity and Social Justice Action Group

- *International Coalition of Cities Against Racism*
  United Nations Educational, Scientific and Cultural Organization
Unpublished allegories

- Dual Reality: A Restaurant Saga
- Conveyor Belt: Stages of Anti-racism
- Japanese Lanterns: Colored Perceptions
- Understanding This Bus We Are On
- Bicycles on a Hill: Equal Opportunity?
- Bus Seating: The Permanence of Privilege
- Bus Survey: Who Counts?
- Airplane Seating: Invisible Tether

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Barriers to achieving health equity

- **A-historical culture**
  - The present as disconnected from the past
  - Current distribution of advantage/disadvantage as happenstance
  - Systems and structures as givens and immutable

- **Narrow focus on the individual**
  - Self-interest narrowly defined
  - Limited sense of interdependence
  - Limited sense of collective efficacy
  - Systems and structures as invisible or irrelevant

- **“Myth of meritocracy”**
  - Role of hard work
  - Denial of racism
  - Two babies: Equal potential or equal opportunity?
Strategies for achieving health equity

- **To change opportunity structures**
  - Understand the importance of history
  - Challenge the narrow focus on the individual
  - Expose the “myth of meritocracy”
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  - Intervene on decision-making processes
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- To value all people equally
  - Break out of bubbles to experience our common humanity
  - Embrace ALL children as OUR children