Mining large data to guide policy and improve health equity

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Outline

Defining and understanding health equity

◦ Words and concepts

◦ The role of public policy

◦ Inequities in mental health and mental health care

Big data – an opportunity to identify and address inequities that carries risks

◦ Bias in AI and why it matters for equity

◦ What it takes to do impactful health equity research

Defining and Understanding Health Equity

Words and concepts

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Health Equity – influential definitions

Braveman. Health Disparities and Health Equity: Concepts and Measurement. Annu Rev Public Health 2006.

Full version: A health disparity/inequality is a particular type of difference in health or in the most important influences on health that could potentially be shaped by policies; it is a difference in which disadvantaged social groups (such as the poor, racial/ethnic minorities, women, or other groups that have persistently experienced social disadvantage or discrimination) systematically experience worse health or greater health risks than more advantaged groups

Briefer version: Health disparities/inequalities are potentially avoidable differences in health (or in health risks that policy can influence) between groups of people who are more and less advantaged socially; these differences systematically place socially disadvantaged groups at further disadvantage on health

"People often use […] health inequalities in what may be an effort to avoid the judgmental or moral connotations that may be associated with health inequities"

Braveman & Gruskin. Defining health equity. J Epidemiol Community Health 2003

World Health Organization Health equity (who.int)

Absence of **unfair, avoidable or remediable** health differences among groups of people based on social stratifiers
Achieved when everyone can attain their full potential for health and well-being

Social stratifiers:
- Socioeconomic position (social class)
- Race and Ethnicity
- Place of residence
- Sex, Gender, or Sexual orientation
- Age
- Disability

Health inequities faced by people disadvantaged based on social stratifiers are compounded by stereotyping, prejudice, and discrimination
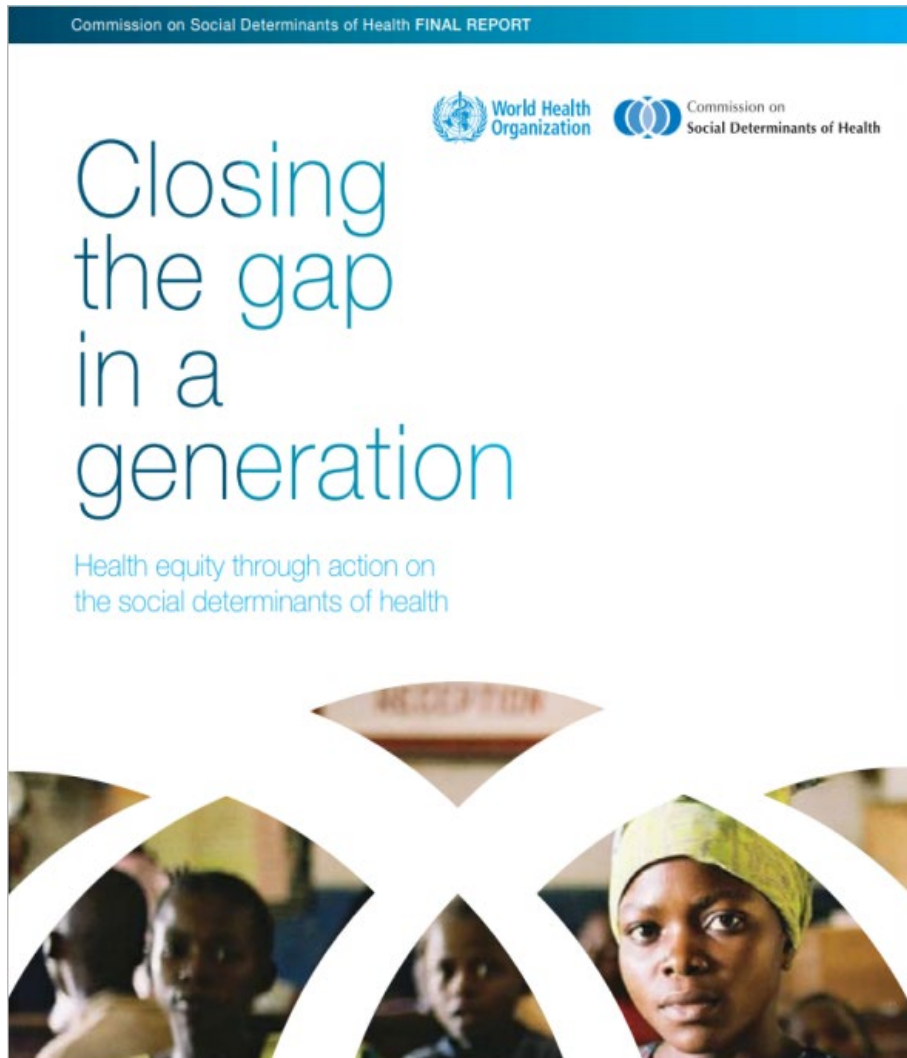
Stereotyping = oversimplified generalizations

Prejudice = biased thinking

Discrimination = bias-driven actions against a group of people

- Discriminatory practices often embedded in institutional and political processes

The role of public policy

CSDH (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization

Understanding Inequities – WHO CSDH's Conceptual Framework*

Health (and disease) regarded as a socially produced phenomenon
◦ Locates health as a social justice topic (human rights framework)

**Health inequities flow from patterns of social stratification**
◦ Social stratification - the systematically unequal distribution of resources, power, and prestige among social groups

Addressing determinants - political process that engages the agency of disadvantaged communities and the responsibility of the state
◦ Emphasis on creative self-empowerment of previously oppressed groups

* Draws from the work of Finn Diderichsen and his *Model of Mechanisms of Health Inequality* [Diderichsen et al. The Social Basis of Disparities in Health. In: Evans et al., eds. Challenging inequities in health. New York, Oxford University Press 2001]

CSDH's Conceptual Framework: Structural and Intermediate Determinants
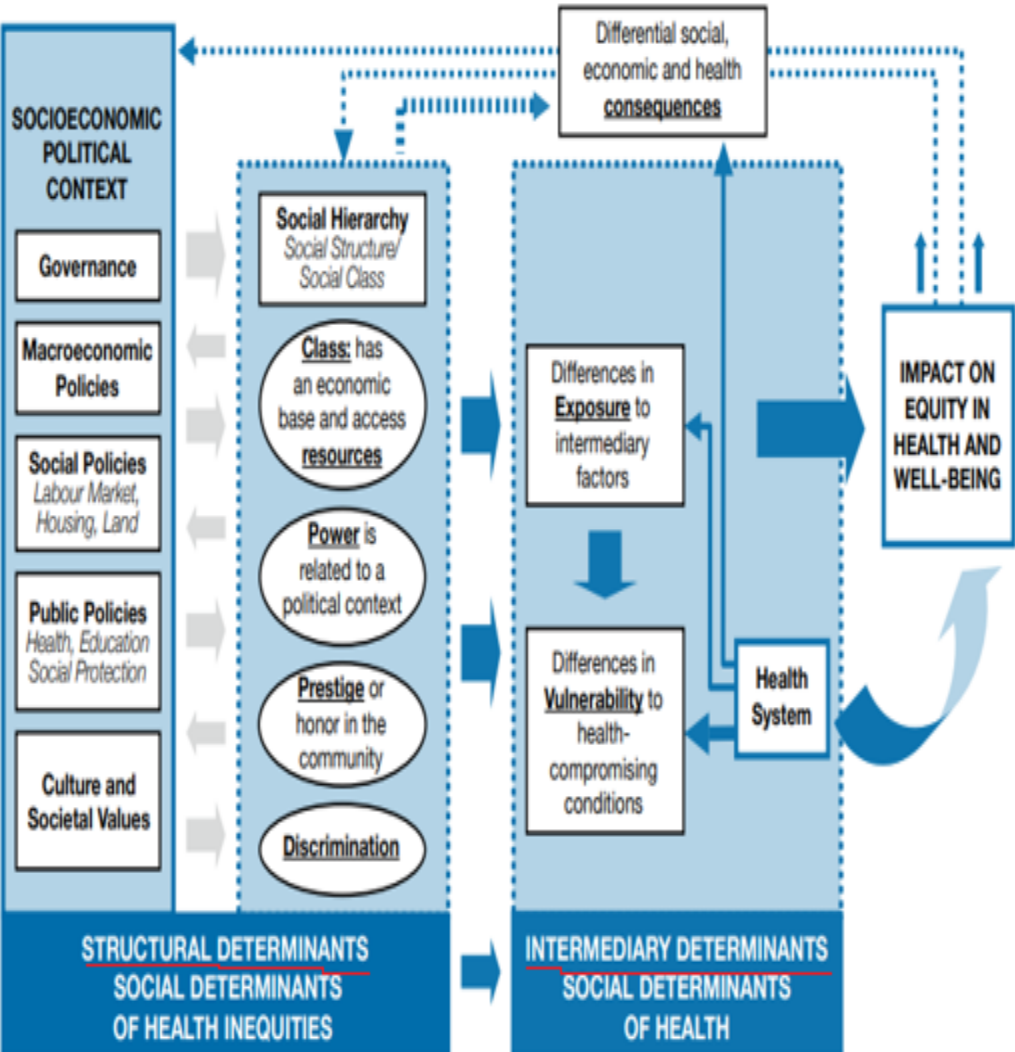
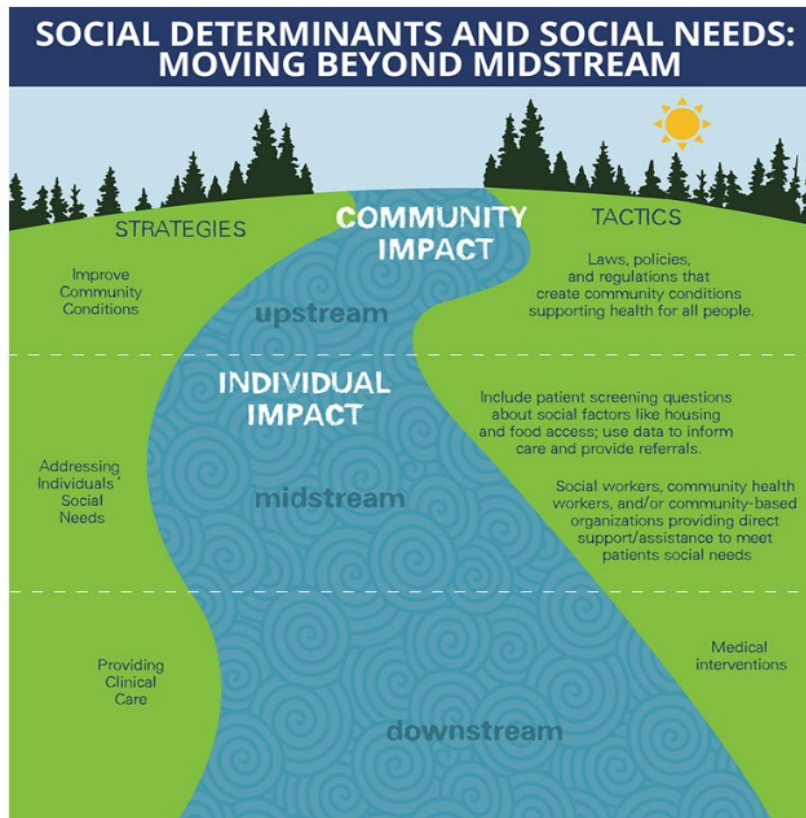**Social Determinants of Health Inequities** - stratifying contextual factors that create social hierarchies

* Groups stratified based on resources, power, and prestige
* Proxy indicators: income, education, occupation, gender, race/ethnicity, disability, others

Social Determinants of Health Inequities influence health through differential exposure to **Social Determinants of Health***

* Material circumstances (e.g., housing, physical environment)
* Psychosocial circumstances (e.g., stress, social support)
* Behavioral and biological/genetic factors
* Health system

* Social determinants of health: conditions in which people are born, grow, live, work, and age

Words and concepts matter if policies seek to address the root causes of health inequities

Castrucci & Auerbach. Meeting individual social needs falls short of addressing social determinants of health. Health Affairs Forefront. 2019

Health	A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity; this includes affording everyone the fair and just opportunity to be as healthy as possible.
Social care	Activities that address health-related social risk factors and social needs.
Social determinants of health	The conditions in which people are born, grow, work, live, and age that affect a wide range of health, functional, and quality of life outcomes and risks.
Social needs	A patient-centered concept that incorporates a person's perception of his or her own health-related needs.
Social risk factors	Social determinants that may be associated with negative health outcomes, such as poor housing or unstable social relationships.
Social services	Services, such as housing, food, and education, provided by government and private, profit and non-profit, organizations for the benefit of the community and to promote social well-being.

SOURCES: Adapted from Alderwick and Gottlieb, 2019; HHS, 2019; WHO, 2010.

Inequities in mental health and mental health care

Schizophrenia and social disadvantage

Onset early in life - first episode of psychosis (FEP) typically in late teens, early 20's

Low prevalence (<1%) but high disease burden

- Disability that can be ameliorated
- Premature mortality that can be prevented

Risk Factors

- Genetic etiological factors (familial clustering)
- **Sociodemographic: age, sex, marital status, employment and educational status, race/ethnicity**
- **Non-genetic etiological factors: Stressful life events, urbanicity, cannabis and other substance abuse**

Worse prognosis in the US relative to other industrialized countries

- Relapses leading to hospitalization or incarceration are common
- Overrepresented among homeless persons
- More than 3 in 4 lack gainful employment & depend on income supports

Illness is costly to US society

- In 2013, total costs = $155.7 billion (healthcare costs: 24%; unemployment: 38%)

Using policy to improve outcomes

Use **health policy** levers to expand access to care and promote high-quality and equitable care

- Enforce and strengthen parity laws
- Reduce barriers for gaining Medicaid coverage
- Increase Medicaid provider rates & budgets
- Improve oversight - penalize abusive practices & network inadequacies
- Invest in educating and training the workforce
- Incentivize high-quality care

- Also, promote reductions in Duration of Untreated Psychosis (DUP)
  - Association between DUP and outcomes
  - In the US: longer DUP for racial/ethnic minorities

Improving Quality And Diffusing Best Practices: The Case Of Schizophrenia

Evidence-based practices tend to be used less than non-evidence-based practices in mental health care.

by Marcela Horvitz-Lennon, Julie M. Donohue, Marisa E. Domino, and Sharon-Lise T. Normand

ABSTRACT: The slow spread of treatments supported by empirical evidence and the rapid diffusion of treatments lacking such support play major roles in the lower quality of mental health care received by people with severe mental illnesses compared with the care of less severely ill people. Further, the rapid spread of treatments that are of low cost-effectiveness limits the system's ability to provide the full gamut of high-value treatments available to treat this vulnerable population. Using the case of schizophrenia, we review the context in which these paradoxical patterns of diffusion have occurred, and we propose policy solutions. [Health Affairs 28, no. 3 (2009): 701–712; 10.1377/hlthaff.28.3.701]
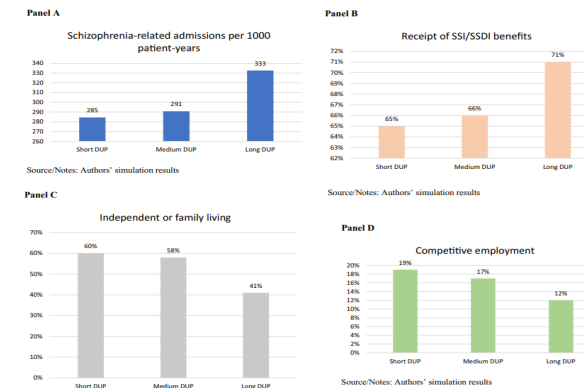
Using policy to improve outcomes

Incentivize equitable care

- Improve race/ethnicity data collection
- Require reporting of data stratified by race/ethnicity and appropriately risk-adjusted
- Incentivize culturally competent care, greater workforce diversity, and disparities reductions
- Ensure that providers caring for disadvantaged individuals are not penalized and paid adequately
- Require that private payers reinvest into the communities they serve

Address modifiable risk factors through social policy

Disentangling inequities by place of residence and race/ethnicity among Medicaid beneficiaries with schizophrenia

The Effect of Race-Ethnicity and Geography on Adoption of Innovations in the Treatment of Schizophrenia

Marcela Horvitz-Lennon, M.D., M.P.H.
Margarita Alegría, Ph.D.
Sharon-Lise T. Normand, Ph.D.

Objective: This study evaluated the effect of race-ethnicity and geography on the adoption of a pharmacological innovation (long-acting injectable risperidone [LAIR]) among Medicaid beneficiaries with schizophrenia as well as the contribution of geographic location to observed racial-ethnic disparities. *Methods:* The data source was a claims data set from the Florida Medicaid program for the 2.5-year period that followed the launch of LAIR in the U.S. market. Study participants were beneficiaries with schizophrenia who had filled at least one antipsychotic prescription during the study period. The outcome variable was any use of LAIR; model variables were need indicators and random effects for 11 Medicaid areas, which are multicounty units used by the Medicaid program to administer benefits. Adjusted probability of use of LAIR for blacks and Latinos versus whites was estimated with logistic regression models. *Results:* The study cohort included 13,992 Medicaid beneficiaries: 25% of the cohort was black, 37% Latino, and 38% white. Unadjusted probability of LAIR use was lower for Latinos than whites, and use varied across the state's geographic areas. Adjustment for need confirmed the unadjusted finding of a disparity between Latinos and whites (odds ratio=.58, 95% confidence interval=.49–.70). The inclusion of geographic location in the model eliminated the Latino-white disparity but confirmed the unadjusted finding of geographic variation in adoption. *Conclusions:* Within a state Medicaid program, the initial finding of a disparity between Latinos and whites in adopting LAIR was driven by geographic disparities in adoption rates and the geographic concentration of Latinos in a low-adoption area. Possible contributors and implications of these results are discussed. (*Psychiatric Services* 63:1171–1177, 2012; doi: 10.1176/appi.ps.201100408)

Although schizophrenia affects less than 1% of the U.S. population (1), it has a much larger societal impact because of its early age of onset, its chronicity, and the resultant significant long-term disability and premature mortality (2). Underuse of recommended interventions is widespread (3), and quality of care is modest at best (4–6). Moreover, persons with schizophrenia who are from racial-ethnic minority groups are less likely than whites to receive recommended interventions (7,8). Although much has been learned about factors associated with adoption of health care innovations (9,10), little is known about whether race-ethnicity influences access to innovative treatments for schizophrenia in the period that follows their release to market (11–13).

Several factors are associated with the existence and persistence of racial-ethnic health service disparities in the United States. The Institute of Medicine conceptualized service disparities as the outcome of both direct race-ethnicity effects and effects mediated by socioeconomic status, insurance coverage, and geographic location of minority groups (14). Geography is treated as a mediator of disparities because it is assumed that for minority groups, geographic location is the result of discrimination and lack of opportunities and not a personal choice (15). As demonstrated by Fisher and colleagues (16), the characteristics of the communities where patients live are associated with the volume and quality of care they receive (www.dartmouthatlas.com/index.shtm). Multiple factors are likely to be implicated in these unwarranted geographic variations in care; key among them are differences in clinicians' treatment practices and other characteristics of the health care system (17). Because racial-ethnic minority groups are not homogeneously

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Disparities in Quality of Care among Publicly Insured Adults with Schizophrenia in Four Large U.S. States, 2002–2008

Marcela Horvitz-Lennon, Rita Volya, Julie M. Donohue, Judith R. Lave, Bradley D. Stein, and Sharon-Lise T. Normand

Objective. To examine racial/ethnic disparities in quality of schizophrenia care and assess the size of observed disparities across states and over time.

Data Sources. Medicaid claims data from CA, FL, NY, and NC.

Study Design. Observational repeated cross-sectional panel cohort study of white, black, and Latino fee-for-service adult beneficiaries with schizophrenia. Main outcome was the relationship of race/ethnicity and year with a composite measure of quality of schizophrenia care derived from 14 evidence-based quality indicators.

Principal Findings. Quality was assessed for 325,373 twelve-month person-episodes between 2002 and 2008, corresponding to 123,496 Medicaid beneficiaries. In 2002, quality was lowest for blacks in all states. With the exception of FL, quality was lower for Latinos than whites. In CA, blacks had about 43 percent of the individual indicators met compared to 58 percent for whites. Quality improved annually for all groups in CA, NY, and NC. While in CA the improvement was slightly larger for Latinos, in FL quality improved for blacks but declined for Latinos and whites.

Conclusions. Quality of schizophrenia care is poor and racial/ethnic disparities exist among Medicaid beneficiaries from four states. The size of the disparities varied across the states, and most of the initial disparities were unchanged by 2008.

Key Words. Racial/ethnic disparities, schizophrenia, quality of care, trends, Medicaid

Trends in quality of mental health care and quality inequities among Medicaid beneficiaries with schizophrenia

ORIGINAL PAPER

Healthcare Access for a Diverse Population with Schizophrenia Following the Onset of the COVID-19 Pandemic

Marcela Horvitz-Lennon[1,2] · Emily Leckman-Westin[3,4] · Molly Finnerty[3] · Junghye Jeong[3] · Jeannette Tsuei[5] · Katya Zelevinsky[6] · Qingxian Chen[3] · Sharon-Lise T. Normand[6,7]

Abstract
COVID-19 has had a disproportionate impact on the most disadvantaged members of society, including minorities and those with disabling chronic illnesses such as schizophrenia. We examined the pandemic's impacts among New York State's Medicaid beneficiaries with schizophrenia in the immediate post-pandemic surge period, with a focus on equity of access to critical healthcare. We compared changes in utilization of key behavioral health outpatient services and inpatient services for life-threatening conditions between the pre-pandemic and surge periods for White and non-White beneficiaries. We found racial and ethnic differences across all outcomes, with most differences stable over time. The exception was pneumonia admissions—while no differences existed in the pre-pandemic period, Black and Latinx beneficiaries were less likely than Whites to be hospitalized in the surge period despite minorities' heavier COVID-19 disease burden. The emergence of racial and ethnic differences in access to scarce life-preserving healthcare may hold lessons for future crises.

Keywords Schizophrenia · Access · Race and ethnicity · Equity · COVID-19

Introduction

COVID-19 has had a disproportionate morbidity and mortality impact on the most disadvantaged members of society, including racial and ethnic minorities and those with disabling chronic illnesses including serious mental illnesses (Chowkwanyun & Reed, 2020; NYC Health, 2020; Webb Hooper et al., 2020). People with schizophrenia are more likely to experience poorer COVID-19 outcomes because of their higher rates of obesity, diabetes, and other pre-existing physical health conditions, and their profound social disadvantage, including higher rates of homelessness (Chen et al., 2020; Druss, 2020; Fond et al., 2021; Jegede et al., 2020; Lee et al., 2020; Murphy et al., 2021; Tsai & Wilson, 2020; Wang et al., 2021). In fact, a study conducted in a New York City healthcare system during the early phase of the pandemic found that schizophrenia was a more significant risk factor for COVID-19-related mortality than heart failure, cancer, and other serious medical and psychiatric conditions (Nemani et al., 2021).

Evaluating access to critical healthcare during the early phase of the COVID-19 pandemic remains an important scientific endeavor as disrupted access may be hard to restore; moreover, treatment discontinuity may lead to illness exacerbations or unrelated declines in physical health, further adding to these individuals' large burden of disease (Druss, 2020; Kozloff et al., 2020). Longstanding drivers of racial and ethnic healthcare disparities may have created more access barriers for minority groups including non-Latinx

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Differences by race/ethnicity in access to critical physical health care during the COVID-19 surge in NYS among Medicaid beneficiaries with schizophrenia

Big data – offers an opportunity to identify and address inequities but it carries risks

Big data can shine a light on health inequities and its drivers

Large observational databases assembled from multiple sources containing varying amounts, types, and quality of health, healthcare, social needs, and social care information

Area-level indices assembled with data from multiple sources (American Community Survey, US Census, etc.) describing SDH at various geographic levels)

Input domains of 15 commonly used social deprivation indices used in the US since 2015

Indices	Domains assessed							
	Economic	Education	Housing and environment	Household structure	Transportation	Race and ethnicity	Insurance	Language barrier
Area Deprivation Index	●	●	●	●				
Social Vulnerability Index	●	●		●	●	●		●
Social Deprivation Index	●	●		●	●			
Material Community Deprivation Index	●	●	●				●	
Community Need Index	●	●	●	●		●	●	●
Distressed Communities Index	●	●	●					
Child Opportunity Index	●	●	●			●		
NCI Census Tract–Level Socioeconomic Status Variable	●	●	●					
Neighborhood Socioeconomic Status Index	●	●			●			
Neighborhood Socioeconomic Disadvantage Index[a]	●			●		●[b]		
AHRQ Socioeconomic Status Index	●	●	●					
Neighborhood Concentrated Disadvantage Index	●			●		●		
Townsend Deprivation Index	●		●		●			
Modified Darden-Kamel Composite Socioeconomic Index	●	●	●		●			
Neighborhood Socioeconomic Status Score	●	●	●					

Trinidad et al. Use Of Area-Based Socioeconomic Deprivation Indices: A Scoping Review And Qualitative Analysis. Health Affairs 2022.

NIST Special Publication 1270

Towards a Standard for Identifying and Managing Bias in Artificial Intelligence

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Bias in AI and why it matters for Equity

The teams involved in AI system design and development bring their cognitive biases, both individual and group, into the process [72]. Bias is prevalent in the assumptions about which data should be used, what AI models should be developed, where the AI system should be placed — or if AI is required at all. There are systemic biases at the institutional level that affect how organizations and teams are structured and who controls the decision making processes, and individual and group heuristics and cognitive/perceptual biases throughout the AI lifecycle (as described in Section 2.4). Decisions made by end users, downstream decision makers, and policy makers are also impacted by these biases, can reflect limited points of view and lead to biased outcomes [73–78]. Biases impacting human decision making are usually implicit and unconscious, and therefore unable to be easily controlled or mitigated [79]. Any assumption that biases can be remedied by human control or awareness is not a recipe for success.

Statistical/computational bias is only the tip of the iceberg
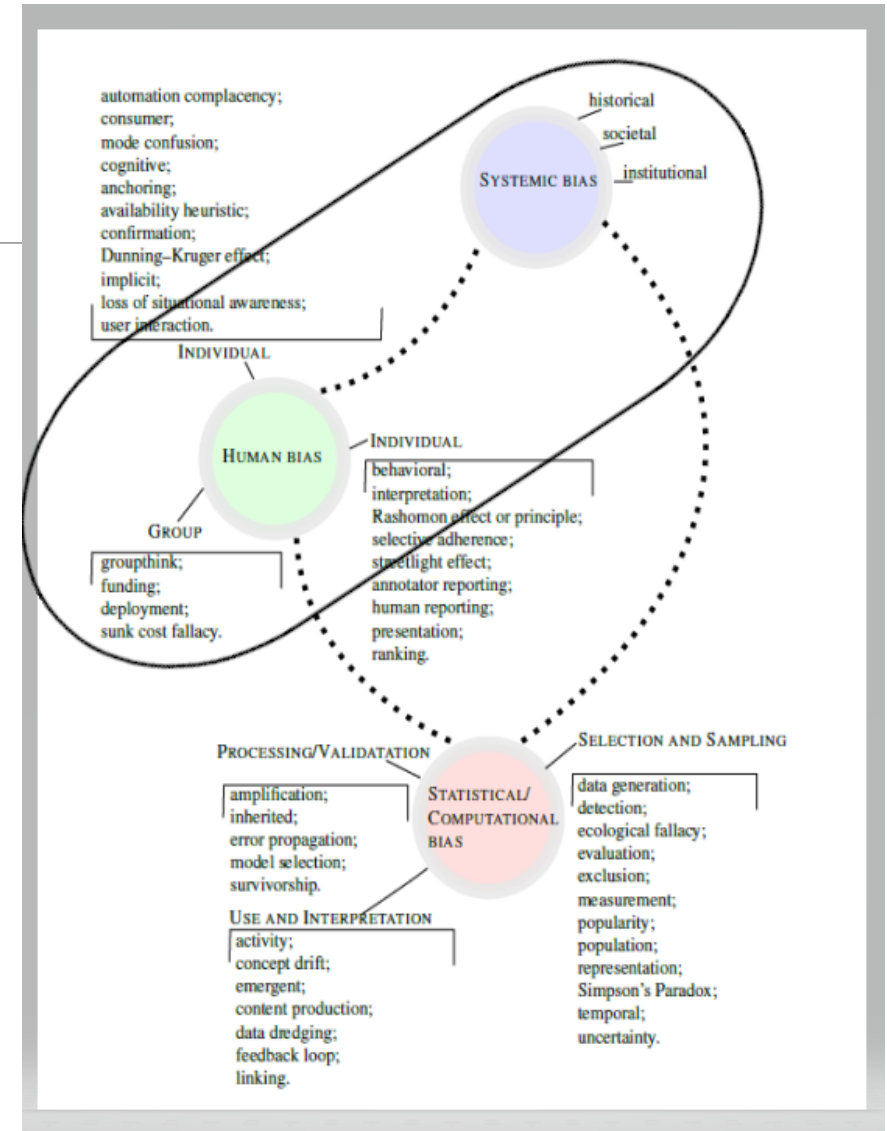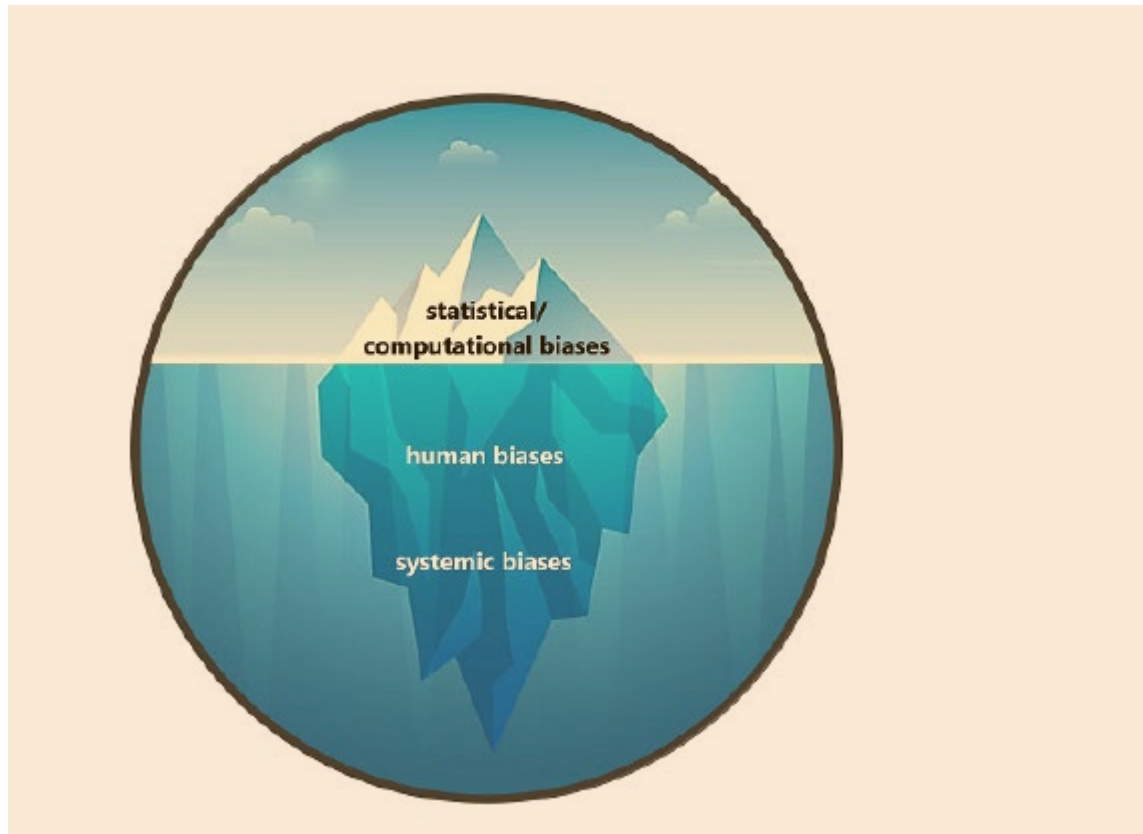
Bias in AI – Statistical and Computational

- Stem from systematic error arising from use of unrepresentative samples
  - Can occur in the absence of prejudice or discriminatory intent

- Present in the datasets and algorithmic processes used in the development of AI applications

- Multiple potential drivers:
  - Heterogeneous or wrong data
  - Representation of complex data in simpler mathematical representations
  - Algorithmic biases
  - Treatment of outliers
  - Others

Bias in AI – HUMAN

Reflect systematic errors in human thought based on a limited number of heuristic principles

Heuristics - adaptive mental shortcuts that permit complexity reduction in tasks of judgement and choice but can lead to cognitive biases

Heuristics and human biases are implicit - increasing awareness does not ensure mitigation

Omnipresent in the institutional, group, and individual decision-making processes across the AI lifecycle and *in the use of AI applications*

Bias in AI – SYSTEMIC

Result from procedures and practices of specific institutions leading to certain social groups being advantaged or favored and others being disadvantaged or devalued

Present in the datasets used in AI; institutional norms, practices, and processes across the AI lifecycle; and broader culture and society

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A way forward

> AI is neither built nor deployed in a vacuum, sealed off from societal realities of discrimination or unfair practices. Understanding AI as a socio-technical system acknowledges that the processes used to develop technology are more than their mathematical and computational constructs. A socio-technical approach to AI takes into account the values and behavior modeled from the datasets, the humans who interact with them, and the complex organizational factors that go into their commission, design, development, and ultimate deployment.

Bias may not be fully eliminated but value of AI may be safely realized only if all AI stakeholders, including policymakers and other end users, are aware of its pervasiveness, sources, and possible mitigation strategies

What it takes to do impactful health equity research

Key ingredients

Develop multidisciplinary hubs of researchers that leverage existing knowledge and other resources and use multiple research methodologies to:

- identify community priorities for addressing inequalities

- deepen the understanding of mechanisms of inequities

- investigate potential additional impacts

- design and evaluate strategies to eradicate them

- motivate and train the next generation of researchers

What it takes to do impactful health equity research

Multidisciplinary hubs of researchers

Disciplines - stress biology and other basic sciences; clinical medicine, psychiatry and other medical specialties; population health; social epidemiology; health services research; health economics; public policy; anthropology

What it takes to do impactful health equity research

Multidisciplinary hubs of researchers
- Disciplines

Methodologies - disparities research, qualitative methods, community-based participatory research, statistical and artificial intelligence methods, simulations, complex systems, translational research, dissemination & implementation research, econometrics, policy analysis & evaluation

What it takes to do impactful health equity research

Multidisciplinary hubs of researchers
- o Disciplines
- o Methodologies

Study designs - randomized trials, quasi-experimental studies, social epidemiological (cohort) studies, qualitative and mixed-method studies

What it takes to do impactful health equity research

Multidisciplinary hubs of researchers
- Disciplines
- Methodologies
- Study Designs

Funding – Heightened interest in health equity research among funders
- NIH study sections and institutes including the National Institute on Minority Health and Health Disparities
- Centers for Medicare & Medicaid Services (Office of Minority Health)
- Patient-Centered Outcomes Research Institute grants
- Foundations (e.g., RWJF-Evidence for Action - E4A: Innovative Research to Advance Racial Equity)
- DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)

THANK YOU

MINING LARGE DATA TO GUIDE POLICY AND IMPROVE EQUITY