Advancing NIH Research on the Health of Women: A 2021 Conference

Beyond Sex as a Biological Variable: Addressing Chronic Debilitating Conditions Among All Women

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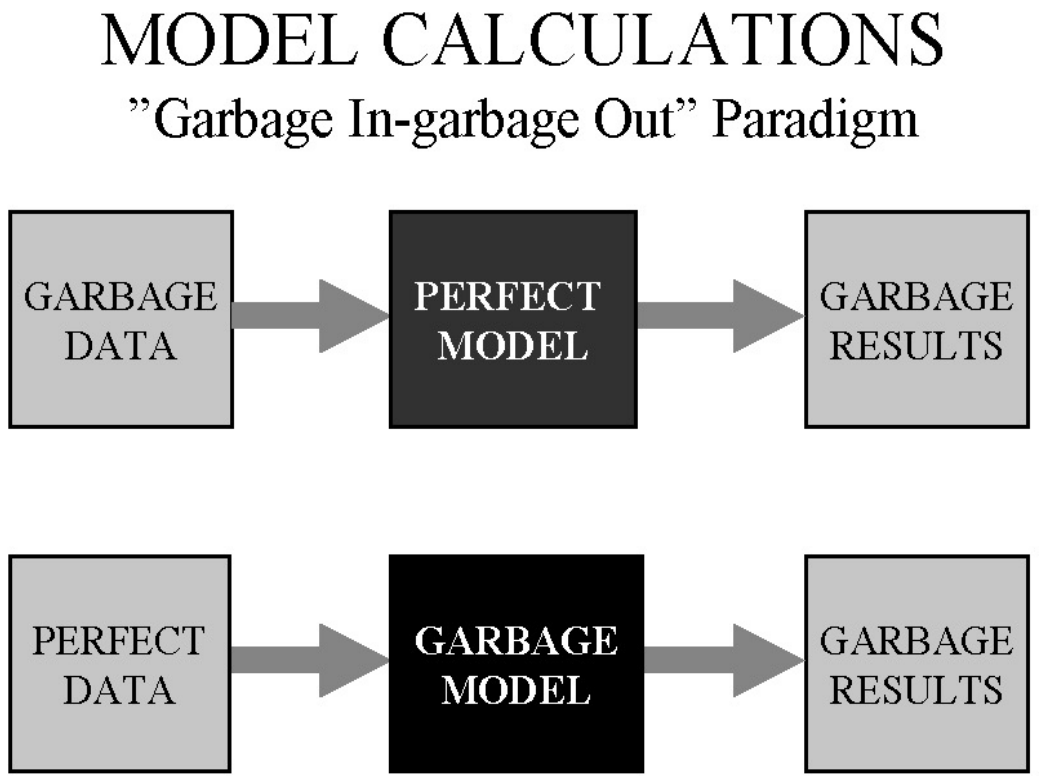
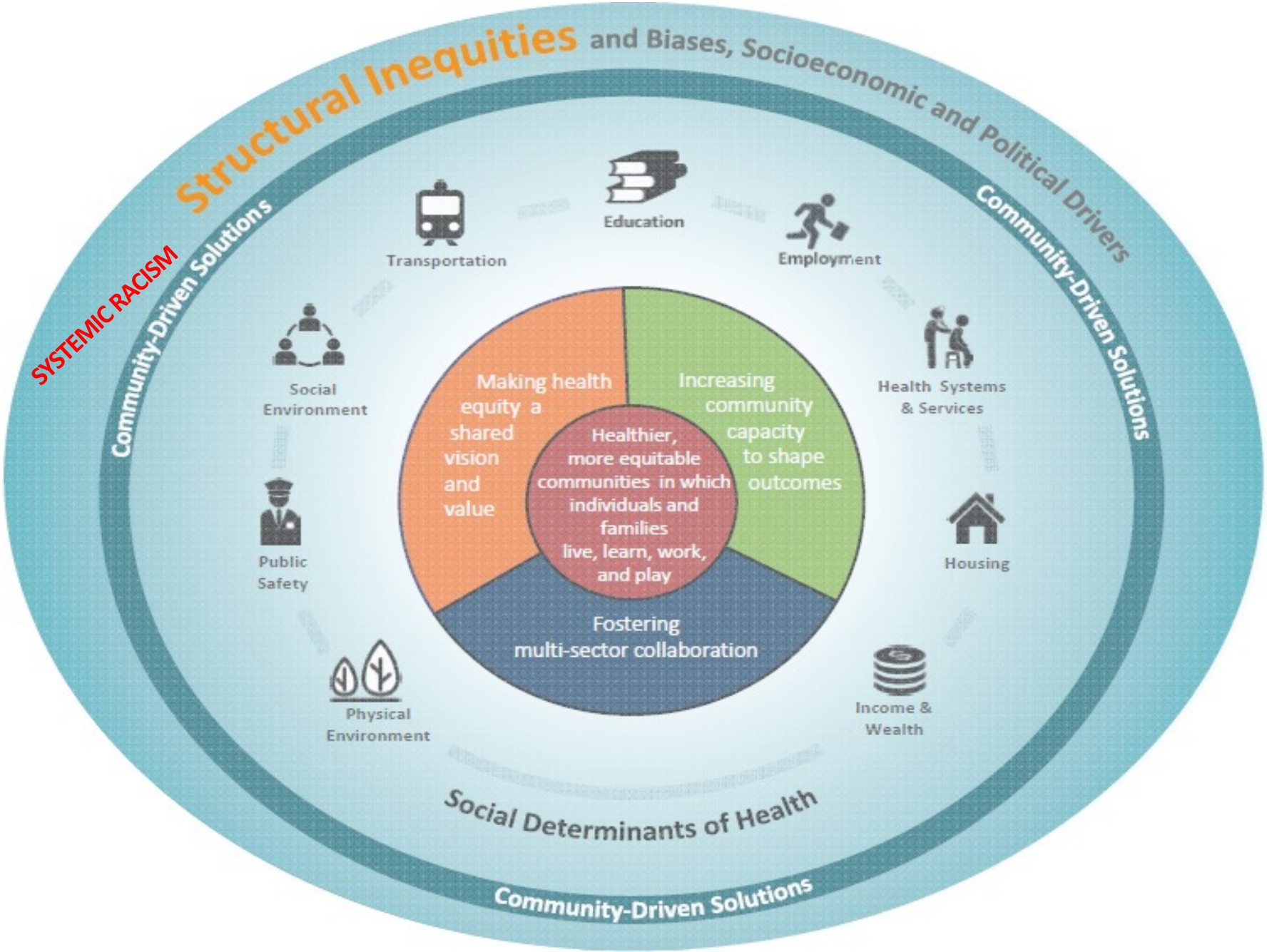
Structure, Design and Inputs Dictate Output

You have to ask the right questions and involve the right people at the table to get the output that is most representative of the issue you are trying to improve.

Asking the right questions is CRITICAL to developing the right solutions.



You have heard today that we know that sex and gender along with the intersection race/ethnicity, SES, stress, and many other social and economic and political factors ("the determinants") profoundly influence cells physiology, metabolism, biological function, symptoms, manifestations of disease, responses to treatment, etc..


Structural Inequities and Biases, Socioeconomic and Political Drivers
SYSTEMIC RACISM
Community-Driven Solutions
Community-Driven Solutions
Transportation
Education
Employment
Social Environment
Health Systems & Services
Making health equity a shared vision and value
Increasing community capacity to shape outcomes
Healthier, more equitable communities in which individuals and families live, learn, work, and play
Fostering multi-sector collaboration
Public Safety
Housing
Physical Environment
Income & Wealth
Social Determinants of Health
Community-Driven Solutions

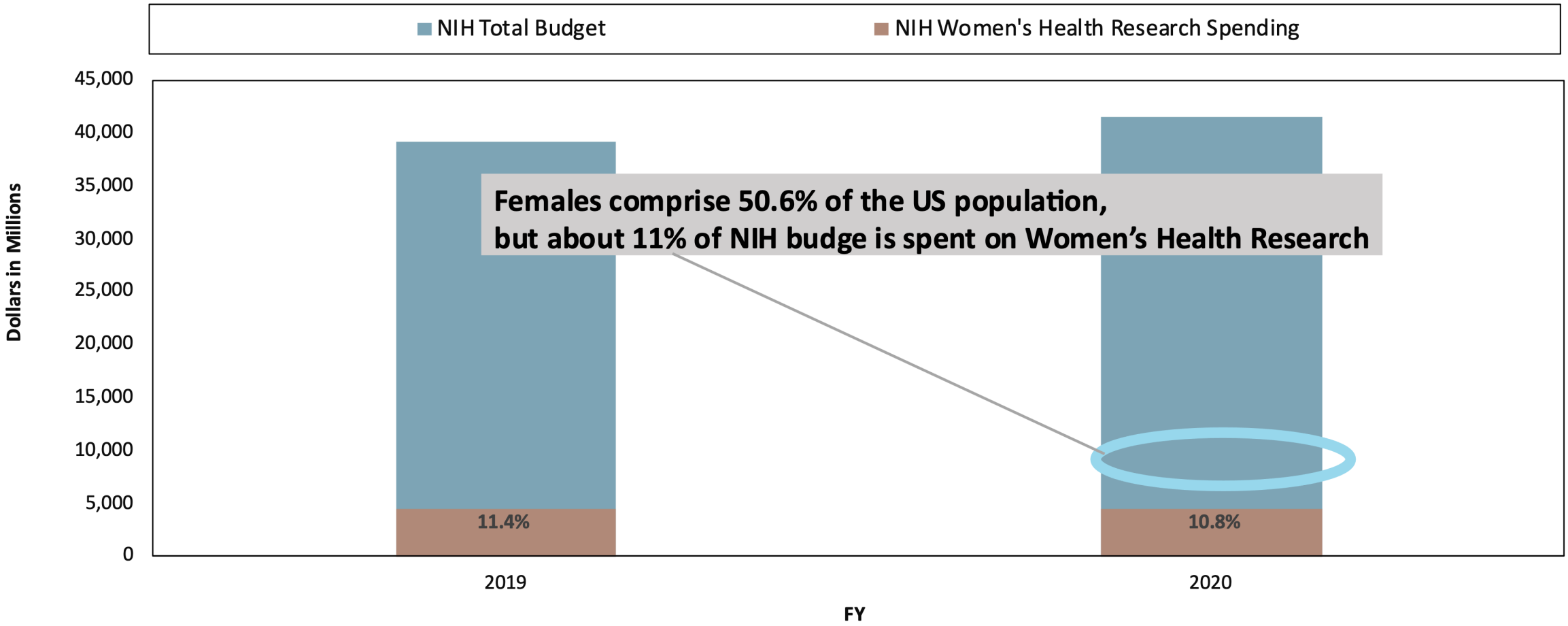
Population of the United States

334, 518, 250 as of Today October 20, 2021

169,375,471 are FEMALES **50.6%** (about 40% are non-white- and our demography is evolving to increasing proportions of non-white persons)

Median age is 38.3 years

Figure 1: NIH Annual Budget and Women's Health Research Spending, FY2019-FY2020



NOTE: The annual budget of ORWH has remained relatively flat since 2003 – ranging from $41 million - $45 million

Sources:

1. Women's health spending data derived from NIH RCDC data system frozen file.
2. NIH total budget excludes buildings and facilities (B&F) costs; data derived from NIH Office of Budget "Appropriations History by Institute/Center" file, https://officeofbudget.od.nih.gov/approp_hist.html.

Disparities in Chronic Debilitating Conditions

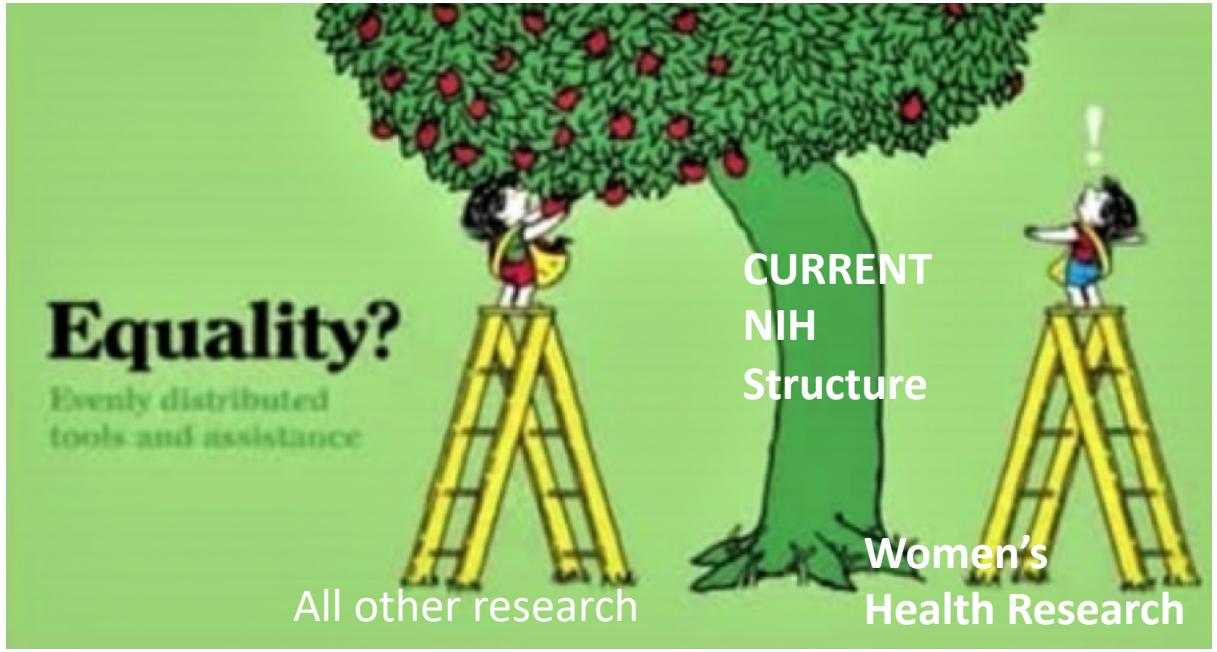
- **Mental Health**: Not only do women bear the brunt of mental health disparities in the US, when the data are examined by race and ethnicity, it is clear that minoritized groups are more likely to experience risk factors that can cause mental health disorders and more likely to persist. AND there are wide access gaps to care
- **Menopause**- Black women experience more symptoms than white women- yet are substantially underrepresented in clinical trials
- The burden of **Cardiovascular Disease, Diabetes, Obesity, Osteoarthritis** and many other chronic debilitating conditions are shouldered by Black and Latina/x women– and **in almost every study women of color are underrepresented**
- Black and Latina/x women have a higher risk of **dementia and Alzheimer's associated Diseases**.
- **Preventive Services** that can prevent chronic debilitating conditions have substantial research gaps that limit the applicability of guideline and recommendation concordant care- (lung cancer screening; Low implementation/uptake in practice; use of preventive medications; behavioral counseling, etc).

Chronic Debilitating Conditions Disproportionately Impact Women- Especially women who are medically underserved, minoritized and marginalized

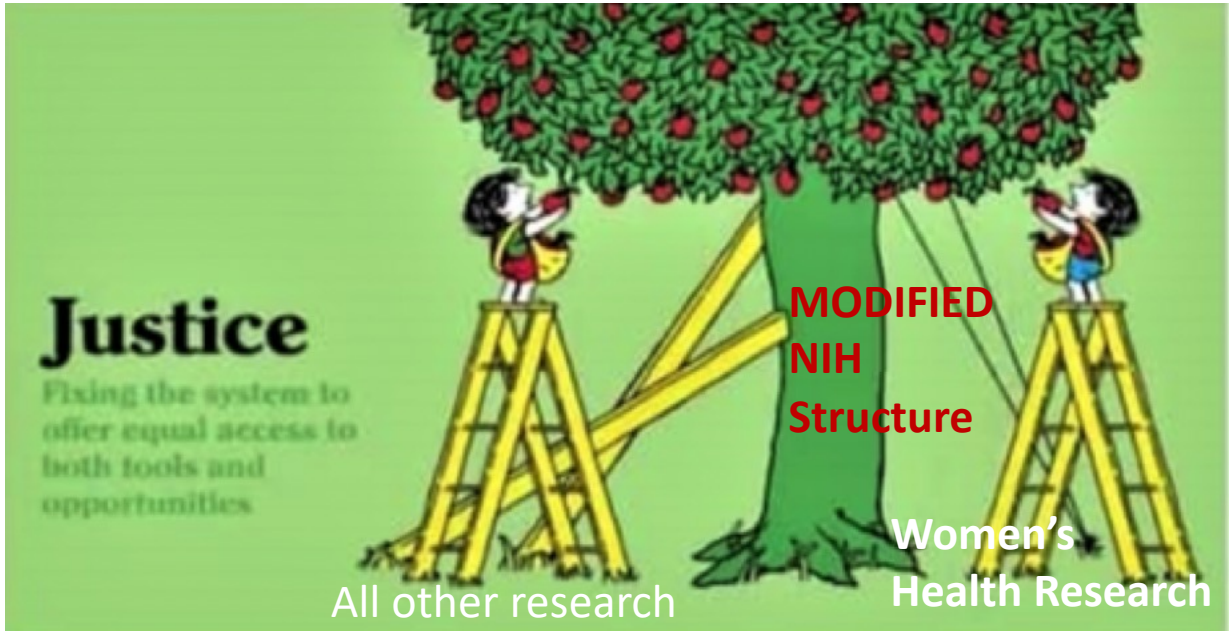
- Not just “more symptoms”, but also “atypical” symptoms and poorer responses to first-line treatments

“Comorbidity” in women is likely a proxy for poorly understood (and inadequately treated) complex morbidity.

Dana E. King, Jun Xiang, Courtney S. Pilkerton. JABFM 2018, 31 (4) 503-513


Equality?
Evenly distributed
tools and assistance
CURRENT
NIH
Structure
All other research
Women's
Health Research

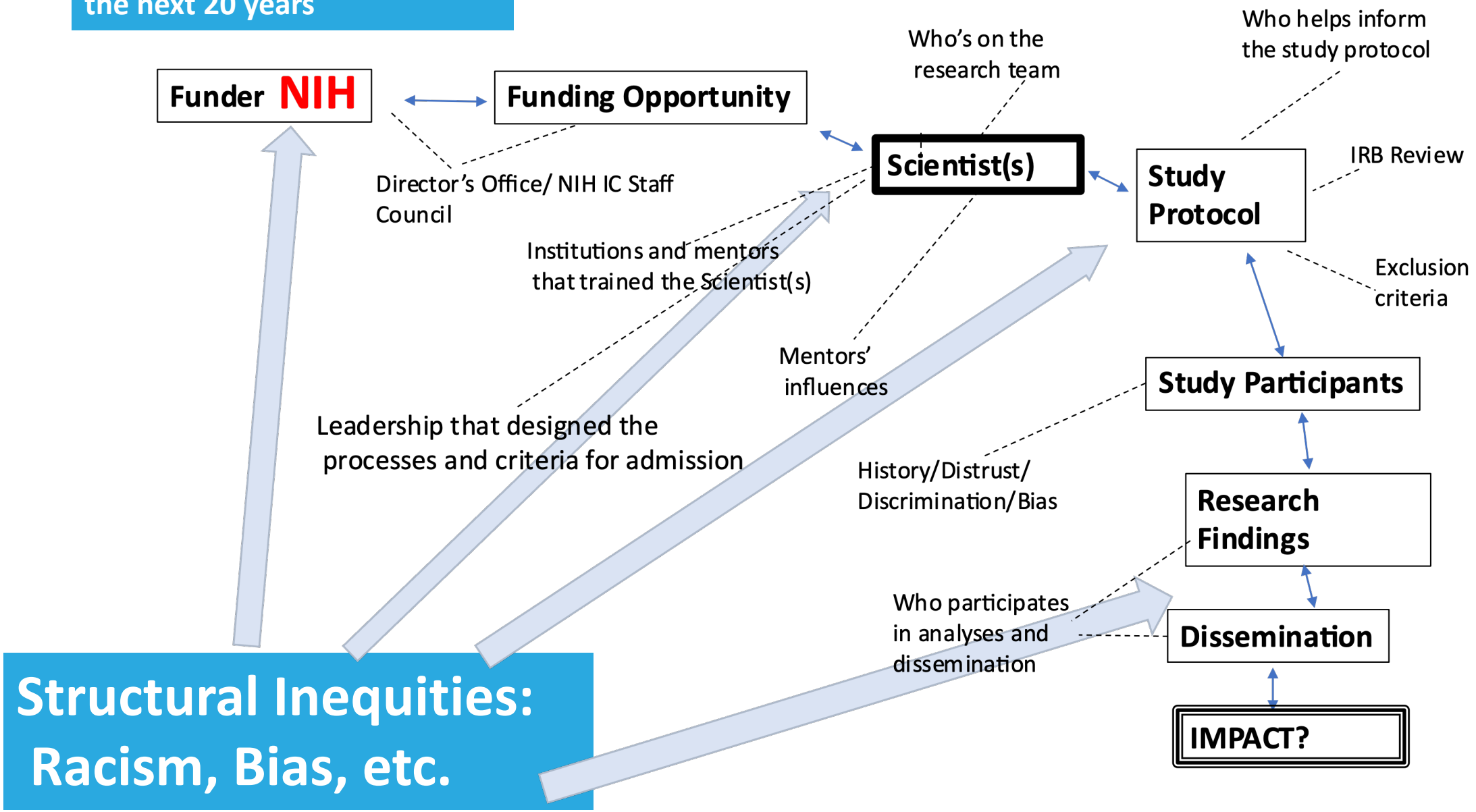
Structure dictates function-
Change the structure



NIH Research should aim to PROTECT ALL Populations

50.6% Females in the US
PLUS: The Evolving Demography of Diversity over the next 20 years

The Structure/Design of the Research Pipeline



50.6% Females in the US PLUS: The Evolving Demography of Diversity over the next 20 years

The Structure/Design of the Research Pipeline

Funder NIH ↔ **Extramural Funding Opportunities**

Majority of submitted and funded research proposals

Investigator Initiated Research- Standing Parent Announcements-(PA, PAR)
allow for the most time to create the proposals and tend to be the most innovative and impactful

UNSOLICITED
Investigator-initiated Research
"Cornerstone of NIH Research Portfolio"

Training Grants, K's OTA's, etc..

IC Staff

Director's Office

Congress

RFA's RFP's

The majority of women's health research is submitted and funded via RFA's
which are less often issued and most often associated with a budget cap and short timeline for submission

Limits time to create a strong innovative proposal

Forces sacrificing other work or home/personal activities

Requires more grant research administrative support in a shorter period of time

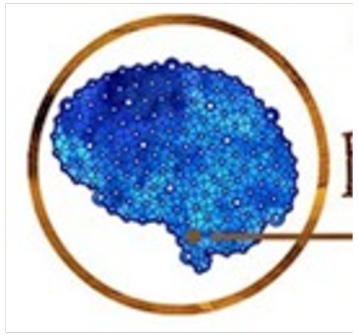
??

Research Findings ?? **IMPACT?**

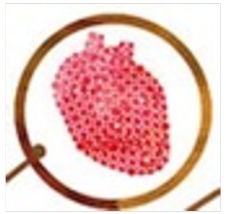
Structural Inequities: Racism, Bias, etc.

The Current Siloed Nature of NIH Funded Research in Women's Health- where is the woman in women's health research?

NIA



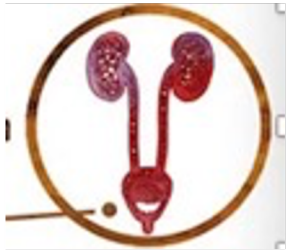
ORWH

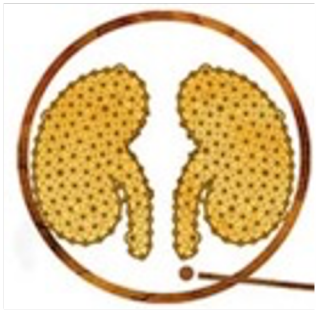


NHLBI

NIMHD

NIMH



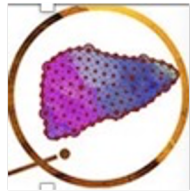


NIDDK

NIDCR

NICHD

NEI



NIAMS

NIAID

NIEHS

NIDA

NIAA

So… our current research funding design that NIH's structure creates does not align with NIH's Mission to "turn discovery into health"

The structure of NIH does not readily allow scientists to comprehensively and adequately address the transdisciplinary and nuanced sex- and gender- specific research needed to address the whole woman and especially women of color and thus does not meet the true women's health clinical care needs…(50.6% of our US population)

What We Need Now:

- A definition of chronic debilitating conditions
- RCDC codes that accurately capture women's health conditions- including Menopause, Menstrual Disorders, PCOS, etc.
- Increased workforce dedicated to women's health research at NIH and across the country. (how do we do this emerging from Covid-19's impact?)
- Standing study sections that comprise women's health research (including obgyn) experts
- Standing grant funding opportunities such as standing parent announcements but that requires grant making authority—
  - Standing parent announcements receive higher proportions of cutting edge research that pushes scientific boundaries of innovation that ultimately improves detection, diagnosis, treatments and cures. If we are lacking this for women's health research – then we are unable to adequately meet the health care needs of 50.6% of the population.

Now more than ever- we need to be intentional

- Increase research funding to focus **not just on women, but ensure diversity in the populations of women**- sex and gender are important but so are race/ethnicity, ses, etc
- The current NIH Structure does not meet the needs of 50.6% of the US population- women.
  - Creating a Center or an Institute that focuses on the advancement of Sex and Gender Research or Women's Health Research at NIH is a pressing need.
    - This could evolve in several ways, the creation of a new Center or Institute vs. the graduation of ORWH from an Office to a Center/Institute vs. the creation of a Center/Institute through multiple offices/centers.
    - Examples include: NIMHD and NCATS
  - Such a structure would confer grant making authority, augment and enhance and promulgate increased women's health research- especially on the three main categories highlighted today in this conference, and would encourage the development of the science workforce to ensure a more steady stream of diverse investigators are excited about and supported to increase research that will improve women's health across the lifespan.
- On October 5, 2021, Dr. Collins said he had doubled the number of women who are institute directors at the NIH. He also said that he hoped his replacement would be a woman.

Instead of this

This is the road to where we want to go

#LiftHealthForAllWomen

Thank you! Join Me!!!

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http://labs.feinberg.northwestern.edu/simon/

Center for Health Equity Transformation
www.feinberg.northwestern.edu/sites/chet/
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Massive Open Online Course
https://www.coursera.org/course/healthcarejobs

Chicago Cancer Health Equity Collaborative
www.chicagochec.org

Podcast --Skinny Trees
www.skinnytreespodcast.com

T37MD14248; NCI P20 233304; R01 MD014068; R01CA163830; U54 CA203000; CA2022995; CA2022997
U54CA221205; G08 LM012688; HD050121; P30 CA060553; NCI NCORP 1UG1 CA189828; NIH P30 AG059304
G08 M013188; R34 MH100443 MH100393; R24MD001650; UG3OD023189; Pritzker Foundation; Merck Foundation/ NCCN
Pfizer Foundation; Avon and Komen Foundations Lynn Sage Cancer Research Foundation, Friends of Prentice
Illinois Department of Health and Family Services, Illinois Breast and Cervical Cancer Program; American Cancer Society