

# CONFESSING OUR PAST, CHALLENGING OUR PRESENT, CONTEMPLATING OUR FUTURE: THE JOURNEY FOR EXCELLENCE IN RESEARCH EQUITY

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## OBJECTIVES

- Review the history and rationale for research in community settings
- Identify ethical and operational considerations in engaging communities and advancing research equity
- Explore strategies for advancing research equity in today's research environment

# COMMUNITY CHATS

- *It's called 'Helicopter Research.' They flew in, took our personal info, took off. We never got anything back. We feel used!*
- *The academics got a grant for reducing smoking but what we're really concerned with is gun and gang violence.*
- *Did they need to do that long study to 'prove' what we already knew?*
- *The professor can't just walk in and create a partnership. It takes time to understand each other.*
- *They want to interview me, have access to my clients, help them with a class or a paper. I don't have time.*



# WHAT IS A COMMUNITY?

(DUNBAR-JACOBS & HIPPS, 2006)

- “A defined geographic or political area
- A population that possesses common characteristics
- An entity that functions in society and outside the researcher’s institution”
- **How do you define community?**

# WHAT IS COMMUNITY-ENGAGED RESEARCH?



- Approach characterized by collaborative partnership development, cooperation & negotiation, & commitment to addressing local health issues
- Two approaches:
  - Limited community engagement/minimal collaboration/partnership only in geography
  - Community organizations & researchers are equal partners in all aspects of the research

# WHAT IS COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

*A **collaborative** approach to research that **equitably involves all partners** in the research process and recognizes the unique strengths that each brings. CBPR begins with a research **topic of importance to the community** and has the aim of combining knowledge with **action** and achieving social change...”*

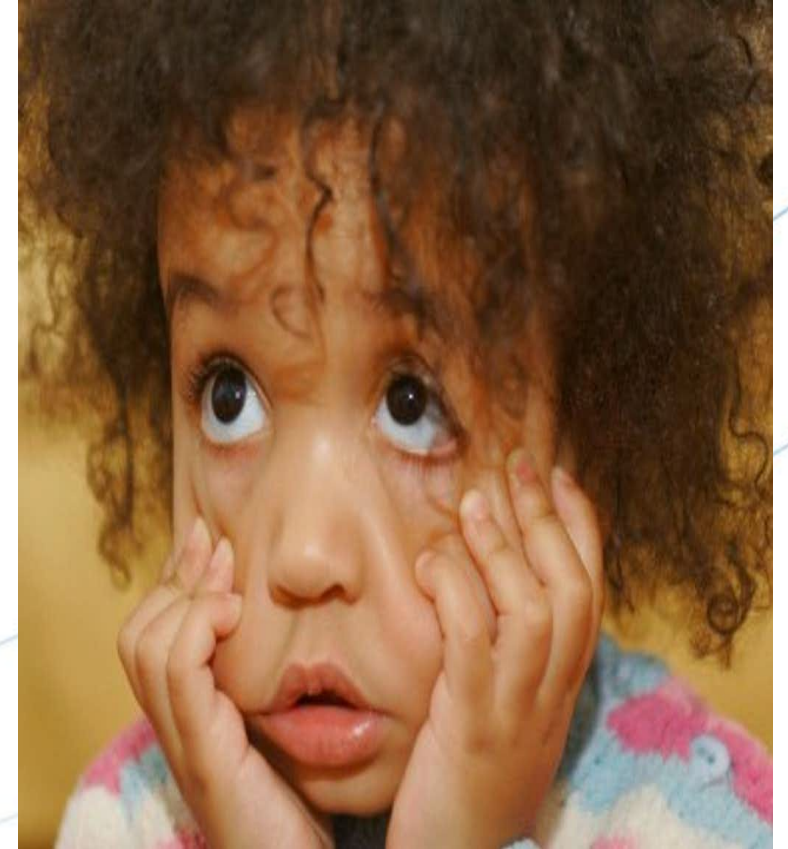
~W K Kellogg Community Health Scholars Program

CBPR embraces greatest degree of relationship building, community partnership & collaboration



# WHAT IT IS AND IS NOT...

- An Orientation to research : changes the role of researcher and researched
  - How can you tell if research is community-placed or community-engaged?
  - Who makes the decisions? Who holds the power? Choice of issue/design, gets money, owns data, dissemination venues
- **Not** a method or set of methods
- Goal is to influence change in community conditions, norms, systems, programs, policies



# BENEFITS OF ENGAGING COMMUNITIES IN RESEARCH

- Research agenda (diversity of topics)
- Research design and delivery (tools, recruitment)
- Research ethics (consent, ethical acceptability)
- Impact on communities (CBOs, participants)
  - Enhancing effectiveness of interventions
  - System change outcomes (policy change, practice/program changes, community capacity and empowerment)
- Impact on broader community/practice





# CURRENT REALITY OF PARTNERSHIPS

- “Community engagement buzz” in higher education/funding circles
- Predominant model is NOT partnership
- Relationship between partners largely based on individuals & funding
- Often assumption by academics/funders/policymakers that community groups NEED academia
- Communities realizing their power to make the rules
- Big differences between mature & early partnerships



# ASSUMPTIONS

- Research with community partners is inherently more ethical.
- Research which engages the community gives the community more power over the research and makes institutions or universities more accountable.



# HOW DID WE GET HERE?



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# “The Study of Untreated Syphilis in the Negro Male” 1932 - 1972

*“The future of the Negro lies more  
in the research laboratory than in  
the schools” – Dr. Thomas Murrell*



# THE “LACKS EFFECT”

- In 1951, a woman with cervical cancer at Johns Hopkins Hospital had cells removed during a biopsy
- Cells (aka HeLa cells) were cultured and showed resiliency never before seen used worldwide in biomedical research and in the treatment of many diseases
- Cultural and social considerations (the “colored ward”; Hill-Burton Act)
- Informed consent (information and autonomy)
- Human subject definition (cell lines, tissue)
- Rights to profit from scientific advances (who has the right to the profit?)





# HOW DO WE MOVE FORWARD?





# CONSIDERATIONS FOR RESEARCH IN THE COMMUNITY

- Diversity, Inclusion, Equity, and Justice
- Partnership, collaborations, and power
- Community rights and democratic representation
- Ownership and dissemination of findings
- Privacy and confidentiality



# DIVERSITY, EQUITY, INCLUSION, AND JUSTICE

"Diversity asks, 'Who's in the room?'

Equity responds: 'Who is trying to get in the room but can't? Whose presence in the room is under constant threat of erasure?'

Inclusion asks, 'Have everyone's ideas been heard?'

Justice responds, 'Whose ideas won't be taken as seriously because they aren't in the majority?'

Diversity asks, 'How many more of [pick any minoritized identity] group do we have this year than last?'

Equity responds, 'What conditions have we created that maintain certain groups as the perpetual majority here?'

Inclusion asks, 'Is this environment safe for everyone to feel like they belong?'

Justice challenges, 'Whose safety is being sacrificed and minimized to allow others to be comfortable maintaining dehumanizing views?' - Dafina-Lazarus Stewart

# WHICH GROUP IS MORE DIVERSE?



# COMMON CONCEPTUAL MISUSES OF THE TERM “DIVERSITY”

- Diversity defaulting to racial and/or ethnic diversity
- Diversity being used as a synonym for words inaccurately; e.g.
  - Minority
  - Racism
  - Discrimination
  - Underserved
- Referring to a person or a population as “diverse”



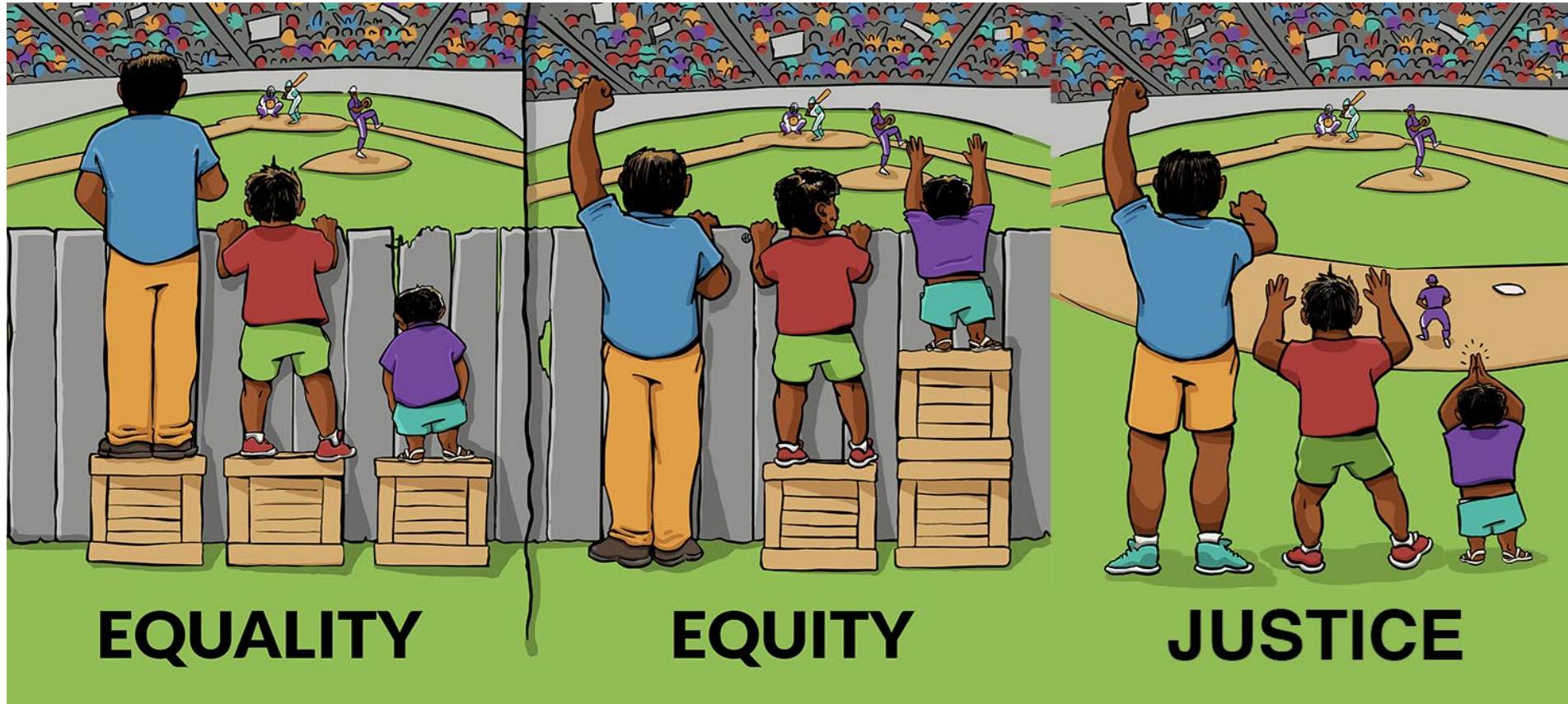


# DEIJ IN TODAY'S RESEARCH ENVIRONMENT

- Applies to research subjects, IRB members, researchers and staff, community engagement and outreach, public health, all direct and indirect stakeholders of the research enterprise
- Diversity: comprehensive celebration of variety
- Equity: fair and impartial treatment without exception
- Inclusion: meaningful in terms of access and opportunity; not a “box checker”
- Justice: conscientious leaders and decision makers who do the right thing because it is the right thing



# EQUALITY VS. EQUITY VS. JUSTICE





# PARTNERSHIP, COLLABORATION, AND POWER

- Social justice
- Understanding of the parameters
- Concept of vulnerability
- Value statement and ROI
- Negotiation leverage



# COMMUNITY RIGHTS AND DEMOCRATIC REPRESENTATION

- What constitutes the community?
- Divisive issues
- Comprehensive representation
- Community norms



# OWNERSHIP AND DISSEMINATION OF FINDINGS

- Data control
- Interpretation of results
- Who decides what gets published?
- Dissemination procedures



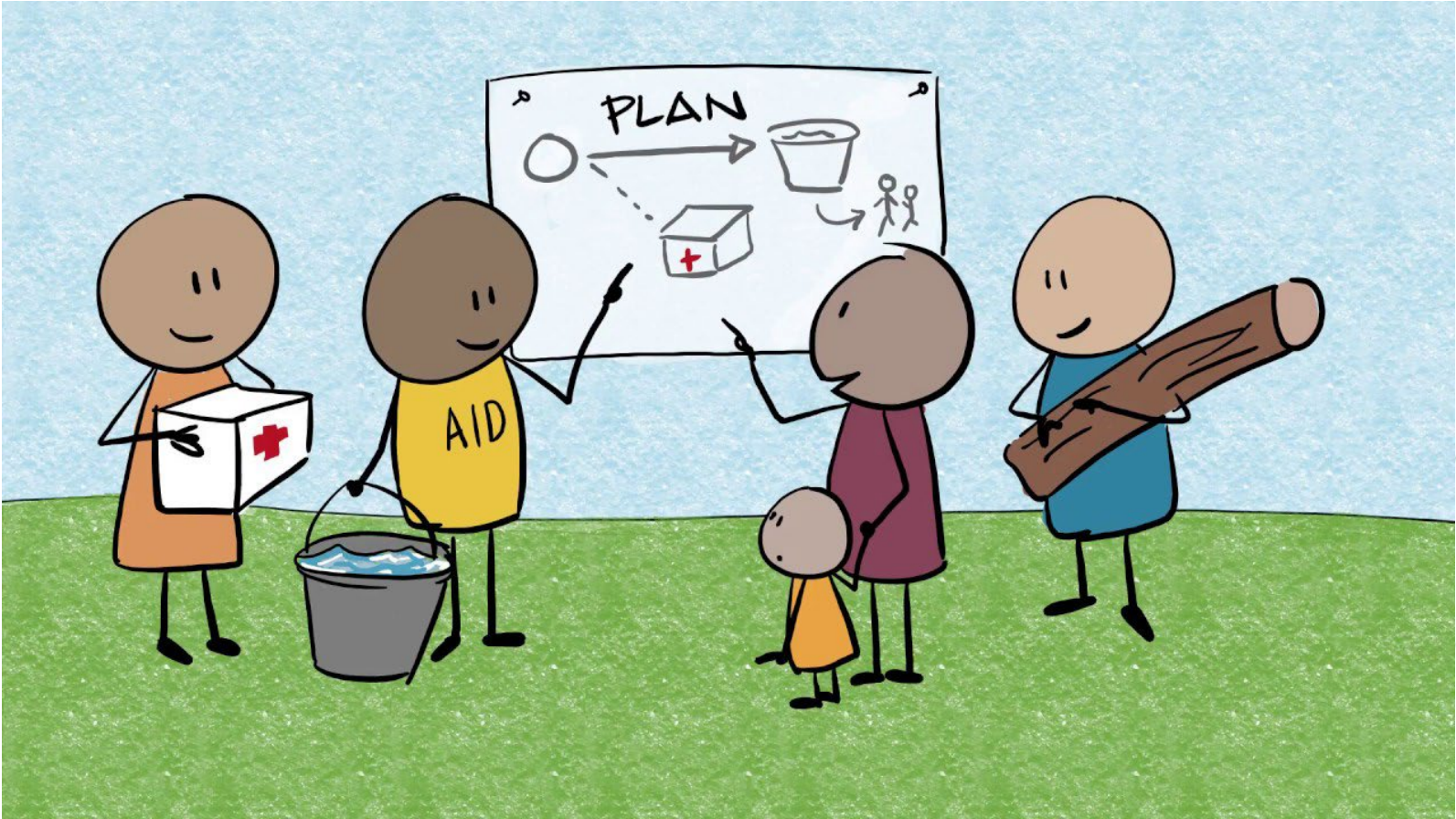
# PRIVACY AND CONFIDENTIALITY

- Informed consent
- Controls for confidentiality
- Community requests for appropriate credit being given
- Description of risks and benefits





# COMMUNITY ENGAGEMENT CONCERNS FROM THE ATTENDEES



# BEST PRACTICES FOR MANAGING ETHICAL DILEMMAS IN COMMUNITY-BASED RESEARCH

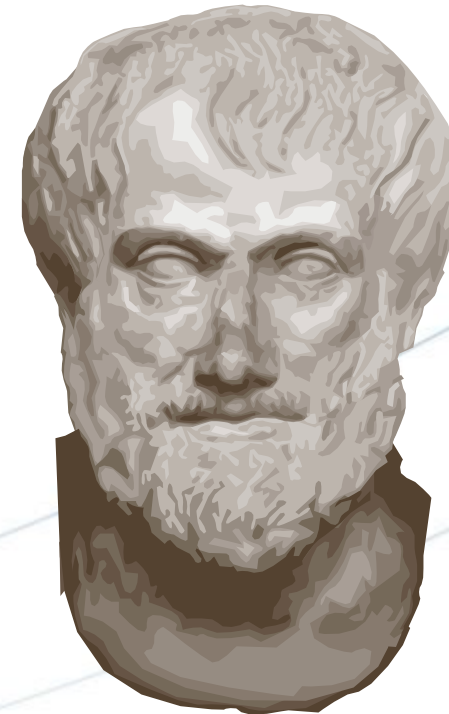
- Practice transparency across the partnership
- Develop best practices to compliment policies and procedures
- Develop an ethical framework – ground rules
- Use team approach to solve problems and make decisions
- Focus on outcomes which consider all the stakeholders – what are the benefits to each partner; Be inclusive
- Educate, assess, then educate again





# ARISTOTLE SAYS:

With regard to  
excellence, it is not  
enough to know, but  
we must try to have  
and use it.



# QUESTIONS AND DISCUSSION

