

Setting the Stage: A Community Perspective

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The Use of Race and Ethnicity in Biomedical Research: A Public Session
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Setting the Stage

A Community Perspective on the Use of Race and
Ethnicity in Biomedical Research, Influenced by
Individual Life Experiences...

Setting the Stage

Defining Terms

- ❑ Race refers to a group sharing some outward physical characteristics and some commonalities of culture and history.

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Defining Terms

- ❑ Ethnicity refers to markers acquired from the group with which one shares cultural, traditional, and familial bonds

Setting the Stage

Defining Terms

□ Biomedical Research is the broad area of science that looks for ways to prevent, the diseases that cause illness and death in people and in animals. This general field of research includes many areas of both life and physical sciences.

Setting the Stage

❑ *Historically,
research has...*

- ❑ Rarely directly benefited and sometimes actually harmed the communities involved
- ❑ Excluded affected communities from influence over the research process

Setting the Stage

*Historically,
research has...*

- ☐ Resulted in understandable distrust of, and reluctance to participate in, research
- ☐ Been labeled by communities as parachute, helicopter or drive-by research
- ☐ Led to interventions that are not tailored to the concerns & cultures of participants, and focused narrowly on individual behavior change

Setting the Stage



Setting the Stage

Commonly Held
Beliefs Include:

- ❑ The process being used against us
- ❑ Possible Exploitation
- ❑ The 'guinea pig' complex

Setting the Stage

Five Commonly shared Areas of Concern:

- ☐ Mistrust or distrust of doctors
- ☐ Mistrust or distrust of scientists
- ☐ The unethical conduct of clinicians and investigators
- ☐ Being misinformed
- ☐ Informed consent

Setting the Stage

- ❑ *“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 Foundation, 2001

Setting the Stage

Creating a space to have these
conversations, where we are inspired and
invigorated; personally and collectively
energized, engaged, and empowered...
having experienced
the e-zone

Setting the Stage

If you are in:

- ☐ A space where you are able to share and receive information
 - ☐ You are in an e-zone

Setting the Stage

If you are in:

- ☐ A space where you not only show respect but where you are respected...
 - ☐ You are in an e-zone

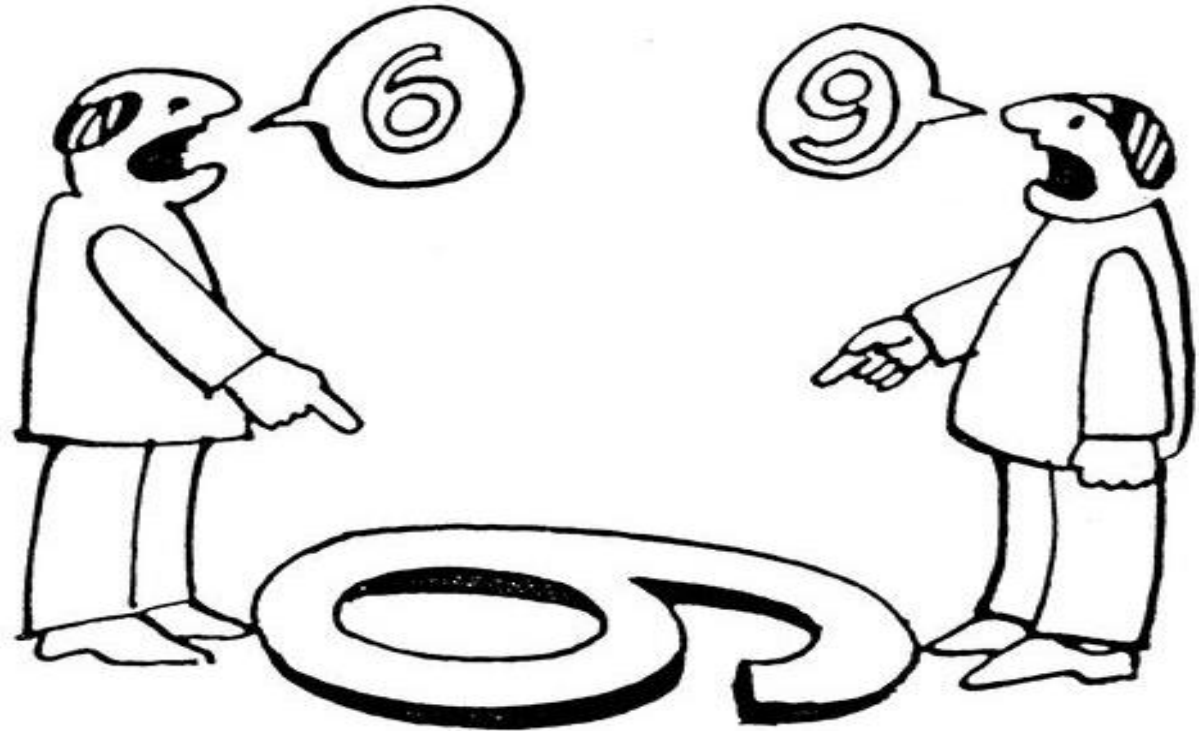
Setting the Stage

If you are in:

- ☐ A space where you are able to recognize, accept, and feel confident enough employing individual and collective power
 - ☐ You are in an e-zone

The Bigger Picture

- Just because you are right does not mean that the other person is wrong... as in this case, it only means that you are looking at it from two totally different views...





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