

# Family and Community: Transforming ideas into practice

- This presentation is dedicated to all of the “Star Student- Good Time Student” hybrids in the room

# Aim

- To think about a complex non-clinical issue in a way that is
  - Systematic
  - Logical
  - Endpoint oriented
  - Feasible
  - Measurable

# Why are we even thinking about engaging family and community?

- They are inherently competent
- They are inherently resilient
- They are intimately acquainted with their strengths, challenges and history
- They are unique
- They are “insiders”
- They possess a natural infrastructure and resources
- They are available 24/7

# Recognizing that

- 95% of care happens at home or in the community
- Patient, family, and community become therapeutic allies with provider

# Continuity Care Model



# What is the family

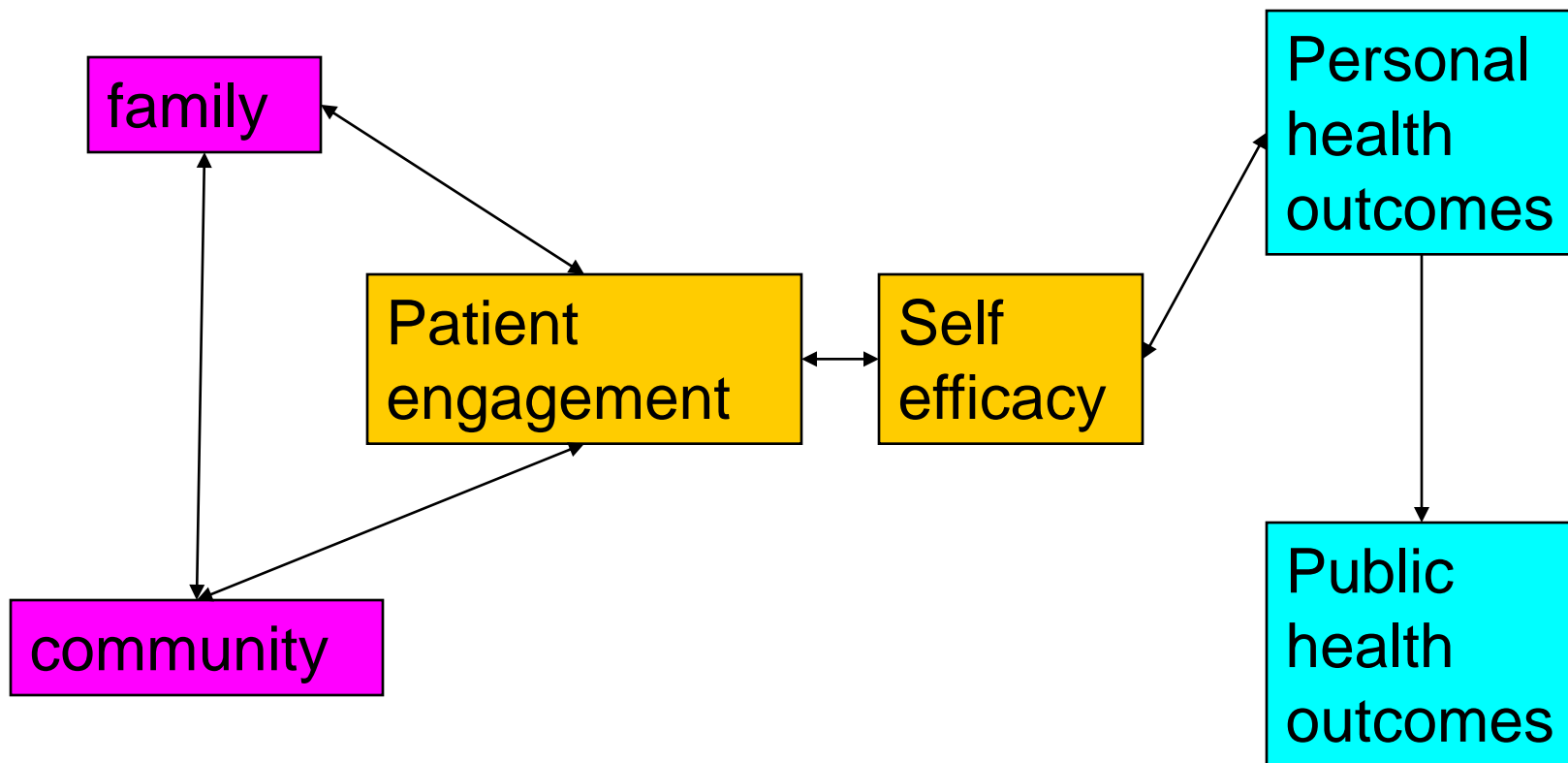
- What kind of group?
- Where do they live?
- How are they bound?
- What functions does it perform?
- Must there be a leader?

# What is the community?

- Geographic
- Common beliefs or interests
- Employment
- Implies
  - Communication
  - Norming
  - Support

# Important point

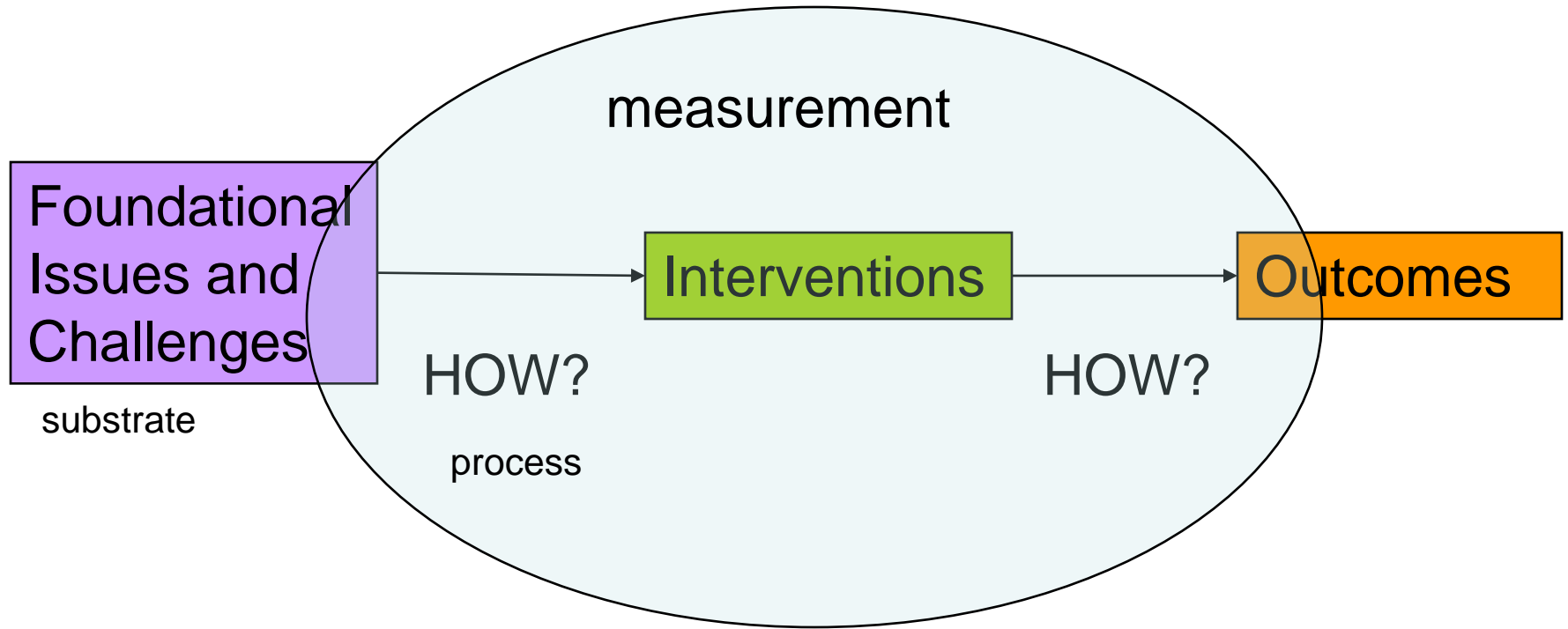
- Individuals (patients) are the building blocks of families
- Family are the building blocks of communities



# Outcomes

- **Decreased maternal morbidity and mortality**
- **Decreased MTCT**
- **Increased HIV-free survival of infants and children**
- **Increased health of family**

Start with this general framework:



- Can start from the right or the left
- But must always keep the other end of the model concretely in mind

# Working from the right: Can break it down

- Know your endpoints/outcomes
- Determine what can be done to meet them
- Determine if this is feasible - what are your resources?
- Know how you intend to measure it
  - Ensuring you are measuring what you set out to do and accomplish
- Know your substrate/foundational issues

# And now from the left....

- Foundational Issues (Substrate)
  - Things that are different
  - Things that are the same

# Special challenges related to peds and pmtct

- Lifecycle
- Developmental stages of children
- Special needs of pregnant women and babies

# But what's the same?

- Stigma
- Continuity care in general
- Family structure and dynamic
  - Developmental stage of family
- Community issues and challenges

# Stigma

- An unfavorable attitude or belief about a person, leading to assumptions about that person, based on one characteristic of that person
- Marking certain individuals as unacceptably different, abnormal
- Stigmatizer feels dread, repulsion, superiority
- Stigmatized feels distress, guilt, worthlessness, shame
- Concept of “us” and “them”
- Deep roots in the social world: race, class, religion, gender, nationality
- Deep roots in the medical world: Tb, leprosy, epilepsy, mental illness, mental retardation, physical disability, HIV

# Discrimination

- An act or behavior based on stigma or prejudice

# These may lead to

- Fear of being identified as positive
- Fear of disclosing status
- Fear of accessing care and treatment
- Fear of practicing prevention
- Fear of caring for people with HIV

*Stigma and discrimination intensify the pain and suffering caused by HIV infection*

# And ultimately

- On a personal level
  - Disengagement from care
  - Poor adherence to medicines and care
  - Disempowerment
  - Worse outcomes
- On a programmatic/public health level
  - Lost to follow-up (mothers and children)
  - Poor program adherence (mothers and children)
  - Low testing rates
  - Limited ability to control epidemic (PwP, PMTCT, safe infant feeding)
  - Limited ability to improve survival and abate illness (mothers, exposed and infected babies)

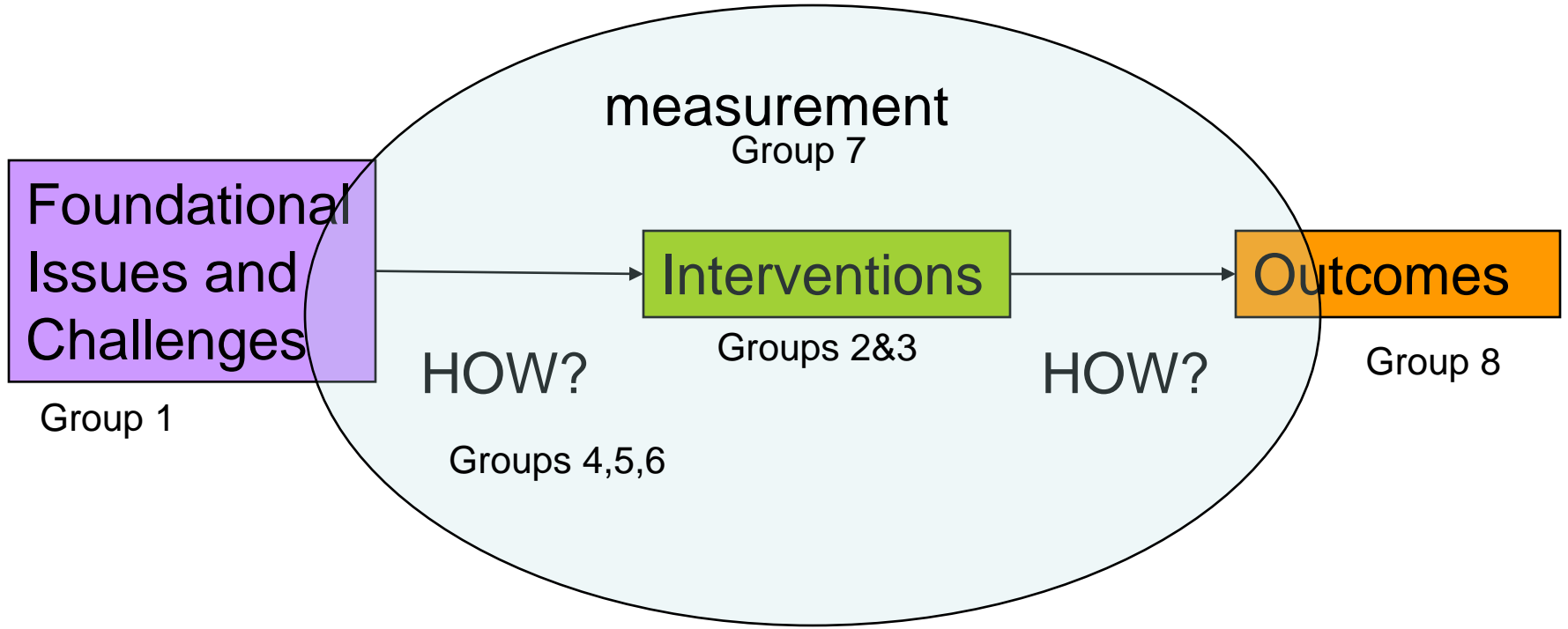
What needs to happen within the family and community to enable patient self-efficacy and improve outcomes?

- Mihayo Bupamba, ICAP-Tz will present a case



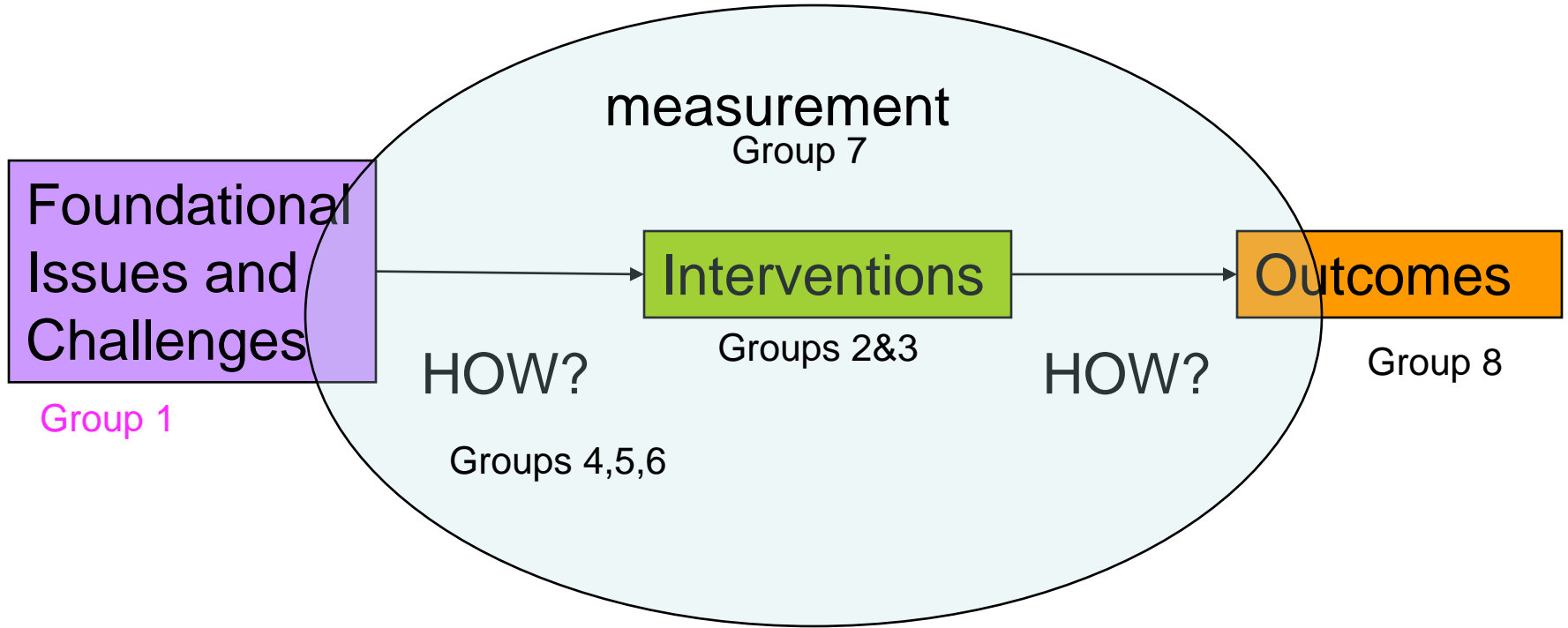
# Small Group Practice

- Using a model to help think through a complex non clinical issue
  - Systematically
  - Operationally
  - In a results-oriented fashion
- We will dissect the components of the model in small groups



- Limitations

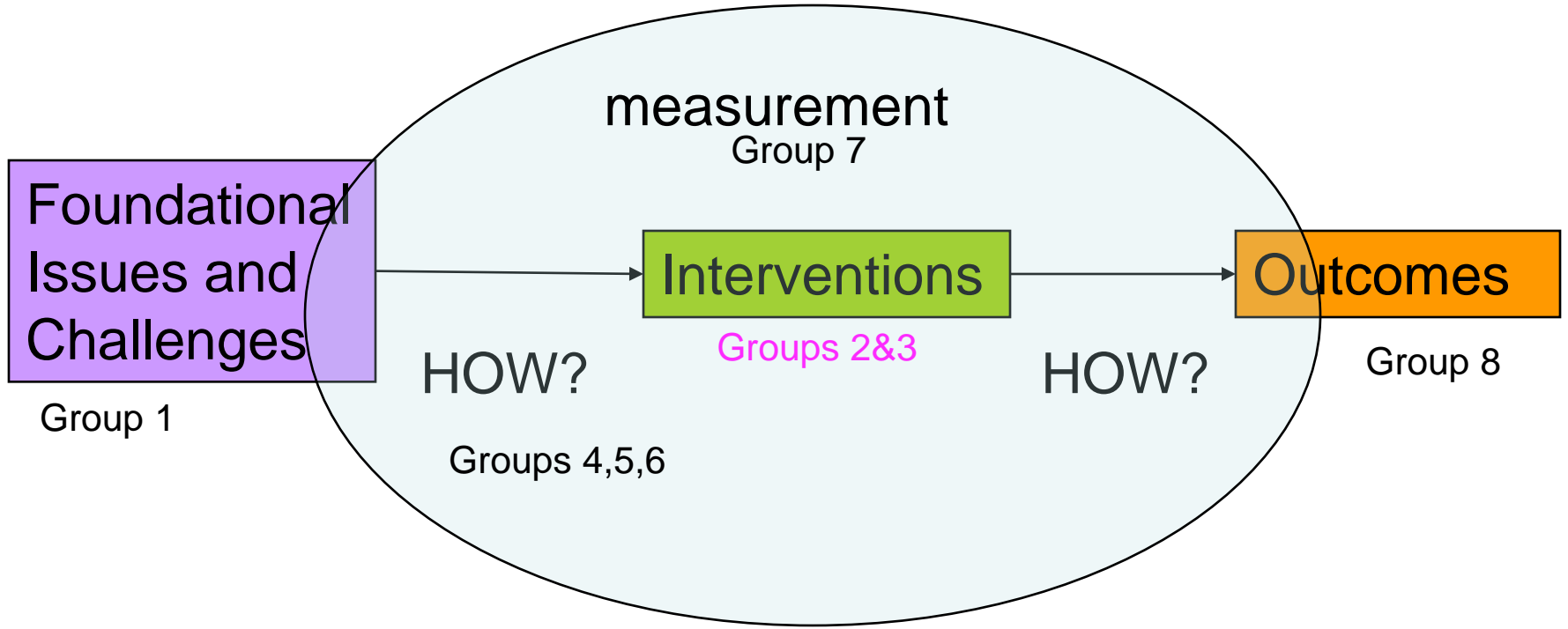
- It is hard to build a model piecemeal
- Certain elements might be culture specific, but perhaps can identify themes
  - Example
    - Husband owns kids (Uganda)
    - Sibling babysitter
    - Mother-in-law makes childrearing decisions (Lesotho)
    - Theme: The household member responsible for (decisions about) the child should be involved in care
- Start from left with outcomes in mind



# FOUNDATIONAL ISSUES

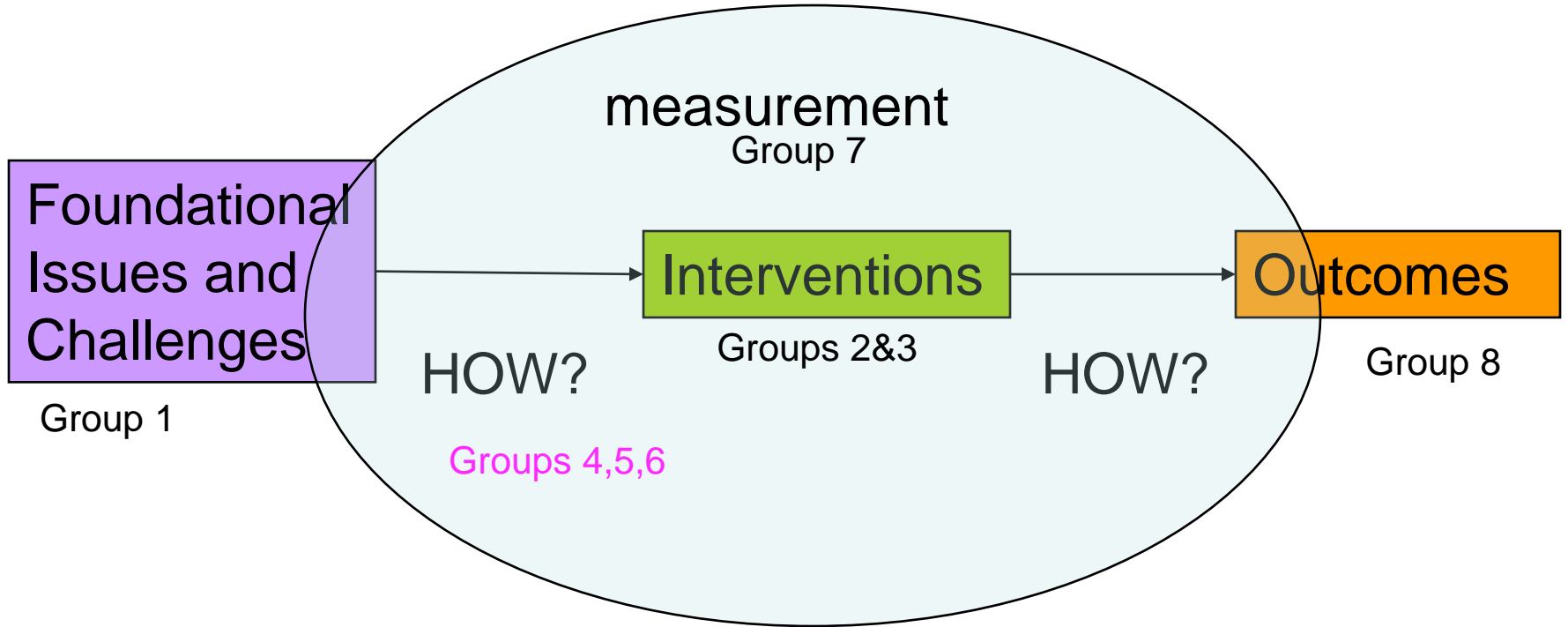
**Group 1:** What are the family and community strengths and challenges specific to HIV and peds/pmtct?

- Example: Lack of disclosure within the family might make patient less able to come to clinic or take meds
- Example: lack of community support might make exclusive breastfeeding difficult
- Example: Mothers might not be aware they should test older children



# WHAT INTERVENTIONS?

- **Group 2:** What are some medical interventions to consider?
  - Example: Mobile clinics might make services more accessible
  - Example: Community testing stations might make testing normalized, enabling more people to test
- **Group 3:** What are some non-medical interventions to consider?
  - Example: Home visits might make all family members feel a part of the care plan
  - Example: Educational sessions might make the community more sensitive, reducing stigma



Foundational  
Issues and  
Challenges

Group 1

measurement  
Group 7

Interventions

Groups 2&3

Outcomes

Group 8

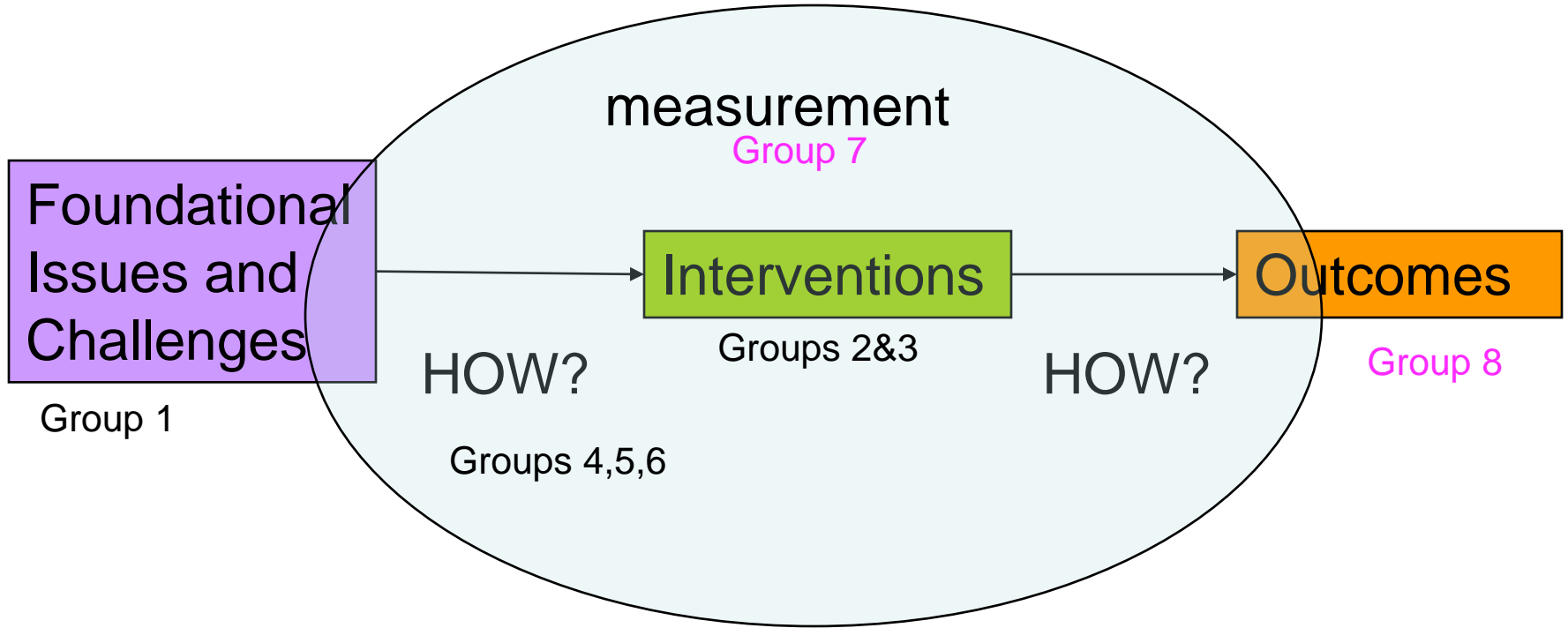
HOW?

HOW?

Groups 4,5,6

# HOW?

- **Group 4:** How can we build community in the clinic; clinic in the community?
  - Example: Multifaceted peer organizations with youth groups
- **Group 5:** How can we linking community and clinic; clinic and community?
  - Example: Staff exchange
- **Group 6:** What are the relative advantages of building new communities and linkages versus strengthening old ones?



# MEASUREMENT CHALLENGES

- **Group 7:** What are some challenges and solutions to identifying family members, their roles, and the dynamics ON AN ONGOING BASIS?
- **Group 8:** What are our outcomes?
  - **Decreased maternal morbidity and mortality**
  - **Decreased MTCT**
  - **Increased HIV-free survival of infants and children**
  - **Increased health of family**
- what might be surrogates or prerequisites to these outcomes (ie, improved patient and family engagement, shifting community attitudes, etc)

- Give concrete examples as well as brainstorm
- Worksheets will be provided
- Present back: 5 minutes per group