

**ICAP Collaborative PMTCT and Pediatric HIV Strategic Planning Workshop  
In Partnership with Tygerberg Children's Hospital, South Africa and S2S**

**Session Notes and Summary**

**Session name:** Plenary Families and Communities: Transforming Ideas to Practice

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**Major Discussion Points from slideset:**

*Why are we thinking of engaging family and community?*

Cultural context, decision making

HIV is family disease

Longevity of disease means that patients need to resume functioning within society; place in community

Difficult to implement treatment without family support

Need to decrease stigma and improve adherence

Attend to lifecycle of the family

Engage patients w/community; gain buy-in

*What is family?*

Expansive, can include more than blood ties: family born into as well as those you are around

People sharing feelings and spirit

People that influence you and that you influence

Common identity

People you care for and who care for you

Obligation which can be negative: hate, jealousy, etc...

Family takes you from sense of self to group

*What is stigma?*

Lack of ability to deal with differences

Judgmental, labeling, stereotyping

Negative connotation that person is not normal and not acceptable

Like a swearword

Shame and isolation from other

Q&A from Tanzania and Kenya slide sets

Tanzania:

Peers undergo a ten-day training (7 days classroom and 3 day practical) - challenge as to how to monitor quality of counseling, given minimal training. Expert patients are chosen as peers, so already some experience and they report to a technical coordinator at the site. In order for peers to make a home visit, they must be welcomed by patient (consent). Incentives include certificates and funds. The work is part-time, no fulltime job commitment. MOH was involved in strategy and ICAP was very persistent attending meetings and advocating at each level.

Kenya:

At pilot community center, plan is for adherence and p-s support; distribution of ITNs, pediatric support groups, pediatric-friendly playrooms and activities, adolescent groups and counselors, videos, pregnant women and breastfeeding women support groups.

## **Groupwork:**

### **Group 1: Foundational Issues**

Leadership

Role of men

Resources: can work for or against common beliefs and help or hinder health seeking behaviors

Family and community buy-in and participation

### **Group 2: Medical Interventions**

Community TB screening w/peers

Counseling and testing in community (VCT)

Home-based care – family focus

Community TB treatment in home of HW

Networks of groups at community and facility levels

Mobilize community to be receptive

### **Group 3: Non Medical Interventions**

Peer educator model (scale down and family based)

Escort system

Involve traditional and political leaders to push messages for adherence and retention and endorse activities through participation (ie, TZ president and wife testing)

### **Group 4: How**

Examples: positive teas (take off coats and be at same level)

Art and painting combined with counseling

Clinic organized groups by regions (destigmatize and offer regional support network)

Bring HCW to community to talk with community

Attend to needs of HCW

### **Group 5: How**

Use existing resources: PLWH networks, community groups and gatherings, political structure

Create new resources: Train peers, mothers to mothers groups

Establish linkages to resources: CBOs and FBOs, workplace, unions

### **Group 6: How**

New community: groups living w/HIV and subcommunities – difficult to develop new community and new linkages

Strengthen old/existing community: Already accepted and established, experience and knowledge, minimize duplicating efforts, less funding required, sometimes difficult to penetrate and to change

### **Group 7: Outcomes**

Strategies used in the past:

Family genealogy form (update)

Family mapping on one card

Peers collect and compare information

Information needed: Nuclear, extended, and household information

Location details (address, landmarks, phone#)

Caregiver and family member HIV status, enrollment, DOB, etc...

ART follow-up card: information on treatment, who accompanied, who administered

Persons responsible: Data clerk, receptionist, providers (update charts), peers (use job aids that collect systematic information) counselors

**Group 8: Outcomes**

Work backwards – review results from current interventions to see how it brings about desired outcome; use information in the records