Family-Centered Approaches to the Integration of PMTCT + ECD

LG3: Expanding Access to Services and Protecting Human Rights

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JLICA JOINT LEARNING INITIATIVE ON CHILDREN AND HIV/AIDS

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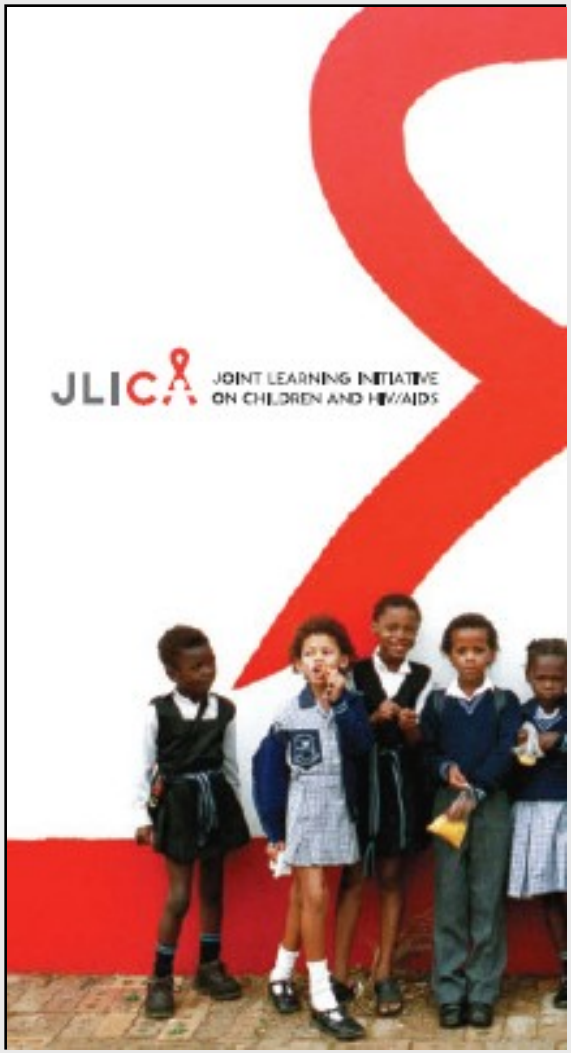
Rwanda Learning Collaborative Health Centers

JLICA LG3 Activities on PMTCT and ECD



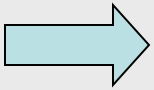
1. Integration and expansion of prevention of mother-to-child transmission (PMTCT)-plus and early childhood development (ECD) intervention services
2. The care delivery value chain in the prevention of mother-to-child HIV transmission
3. Rwanda Learning Collaborative (LC)

Family-Centered Care

"In pediatrics, family-centered care is based on the understanding that the family is the child's primary source of strength and support." (American Acad of Pediatrics, 2003)

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood

Importance of Family-Centered Approaches

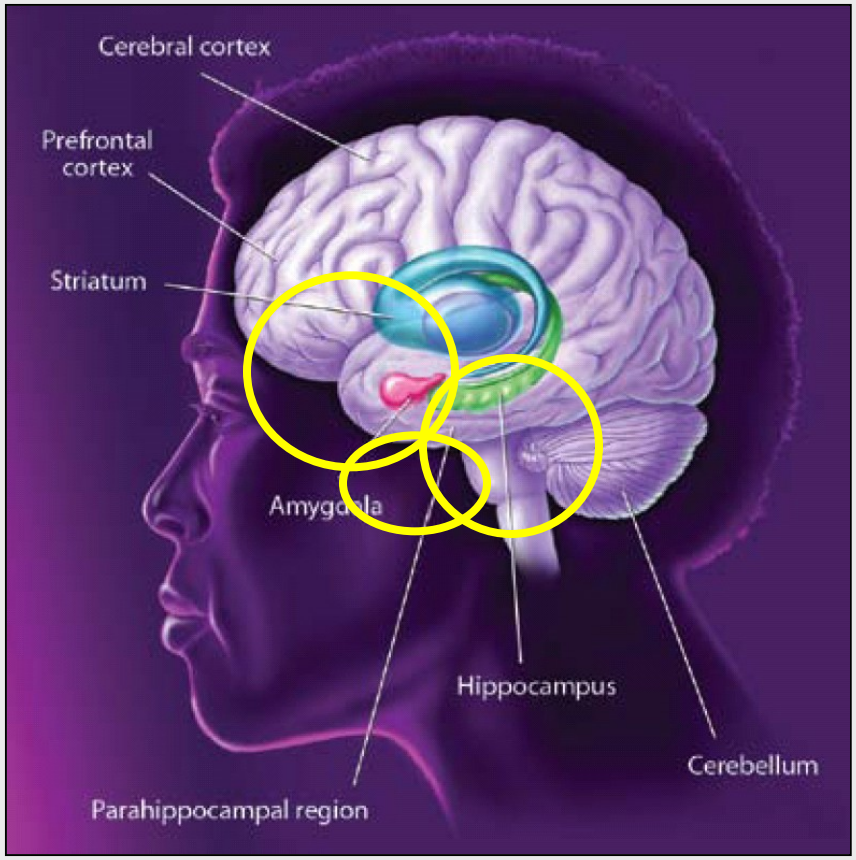
- Lessons learned in two areas: PMTCT and ECD point to the strength of family-centered interventions
- An integrated and family-centered approach to PMTCT and ECD presents an *opportunity*
  - To prevent HIV infection in the infant
  - Increase survival of the mother through HIV treatment
  - Improve overall family health and functioning  thus improving the developmental context for children born into HIV/AIDS affected households

Clear Value of ECD, Particularly for Vulnerable Families

- Lancet series on ECD (Engle et al., Richters et al, 2007)

- The first years of life constitute a critical developmental period for cognitive and emotional development :
  - Social engagement
  - Emotional regulation
  - Stress management
  - Language development

Cognitive, Emotional, and Social Capacities Are Inextricably Intertwined Within the Architecture of the Brain

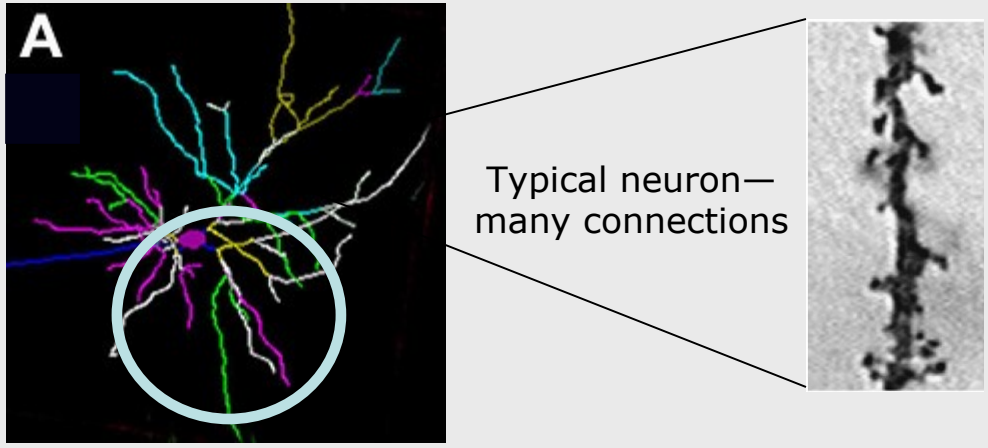


Early Life Experiences Are Built Into Our Bodies (For Better or For Worse)

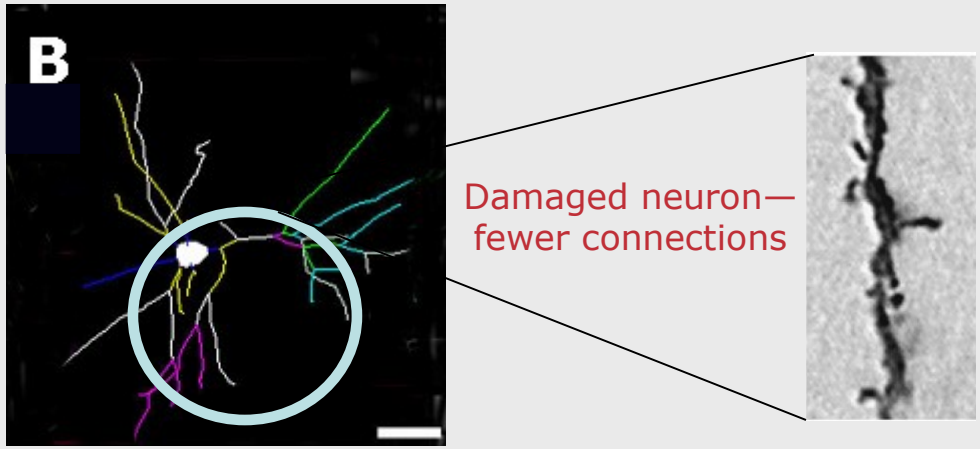
Research on the stress response illustrates how adversity raises heart rate, blood pressure, and stress hormones, which fuels the “fight or flight response” but also poses a potential threat to brain architecture, immune status, metabolic systems, and cardiovascular function.

Toxic Stress Changes Brain Architecture

Normal



Toxic stress



Prefrontal Cortex and Hippocampus

Sources: Radley et al. (2004)
Bock et al. (2005)

Caregiver-child interactions also affected by broader family environment

- HIV-affected families are coping with chronic illness and are vulnerable to:
  - Poverty
  - Limited access to education/ limited literacy
  - Intimate Partner Violence (IPV)
  - Depression and anxiety
  - HIV-related stigma and discrimination
  - Social isolation

Caregiver-child interactions may be impeded by illness or comorbidities such as depression

- High rates of depression or depressive symptoms have been observed among HIV-positive women, ranging from 30-60%

- In turn, this can impact:
  - Maternal sensitivity
  - Maternal negative mood
  - Early stimulation

- Depression in women is affected by broader context of gender inequality, IPV, poverty, all pointing to the need for family-centered approaches

MTCT

- 2.1 million children <15 living with HIV
- 290,000 died of AIDS in 2007
- Most children are infected via transmission during pregnancy,delivery or breastfeeding

PMTCT

- Despite availability of effective regimens and strategies to prevent mother-to-child transmission, a large majority of the pregnant women in resource-limited settings who are HIV-positive (approximately two-thirds) do not have access to PMTCT

- Applying effective strategies, the rate of mother-to-child transmission of HIV can be lowered to < 2%

Barriers to Effective PMTCT

- Limited access to antenatal care (ANC) and obstetric services
- Lack of routine and family-centered HIV testing, lack of counseling at prenatal care clinics
- Poor access to CD4 monitoring
- Poor access to HAART, complex regimens and poor retention in care, etc.
  - Estimated ~ 80% of mother to child transmission of HIV occurs in women who are eligible for HAART based on their own health
- Lack of coordination of services (e.g. of PMTCT with HIV treatment, women's health care, and pediatric care)

Barriers to Effective PMTCT

- Services too centralized to reach remote areas
- Lack of human and material resources
- Psychosocial and family support
  - In Tanzania, women with lower levels of family support were more likely to refuse HIV testing (Kominami et al., 2007)
- Fear of HIV-related stigma
- Limited education and literacy of women
- Gender and power dynamics re: reproductive healt
- Poverty, food insecurity

Address barriers to access and adherence by promoting a *family-centered* approach

- Given the low coverage of PMTCT to date, there is a need for family-centered services to advance coverage and improve outcomes for the entire family

- Many of the barriers to PMTCT plus require an integrated and family-centered approach to care

What Do We Know about Family-Centered PMTCT ?

PMTCT plus (UNICEF, 2006)

- Care for mothers also needs to extend beyond the interventions that prevent their baby from contracting HIV
- The “Plus” represents treatment for parents and other members of the family
- Women living with HIV/AIDS who have recently given birth are the initial contact. Then the child from that pregnancy, other children in the family and the male partner are also enrolled
- Entire family is engaged at an early stage in support services

PMTCT plus

.. also encompasses family planning and reproductive health services, nutritional support, counseling and supportive care, and treatment of other diseases such as malaria and tuberculosis (UNICEF, 2006)

- By 2010, UNICEF endeavors to reach over 2 million women through its PMTCT-Plus program

- This expansion will prevent an estimated 1 million new infections in children

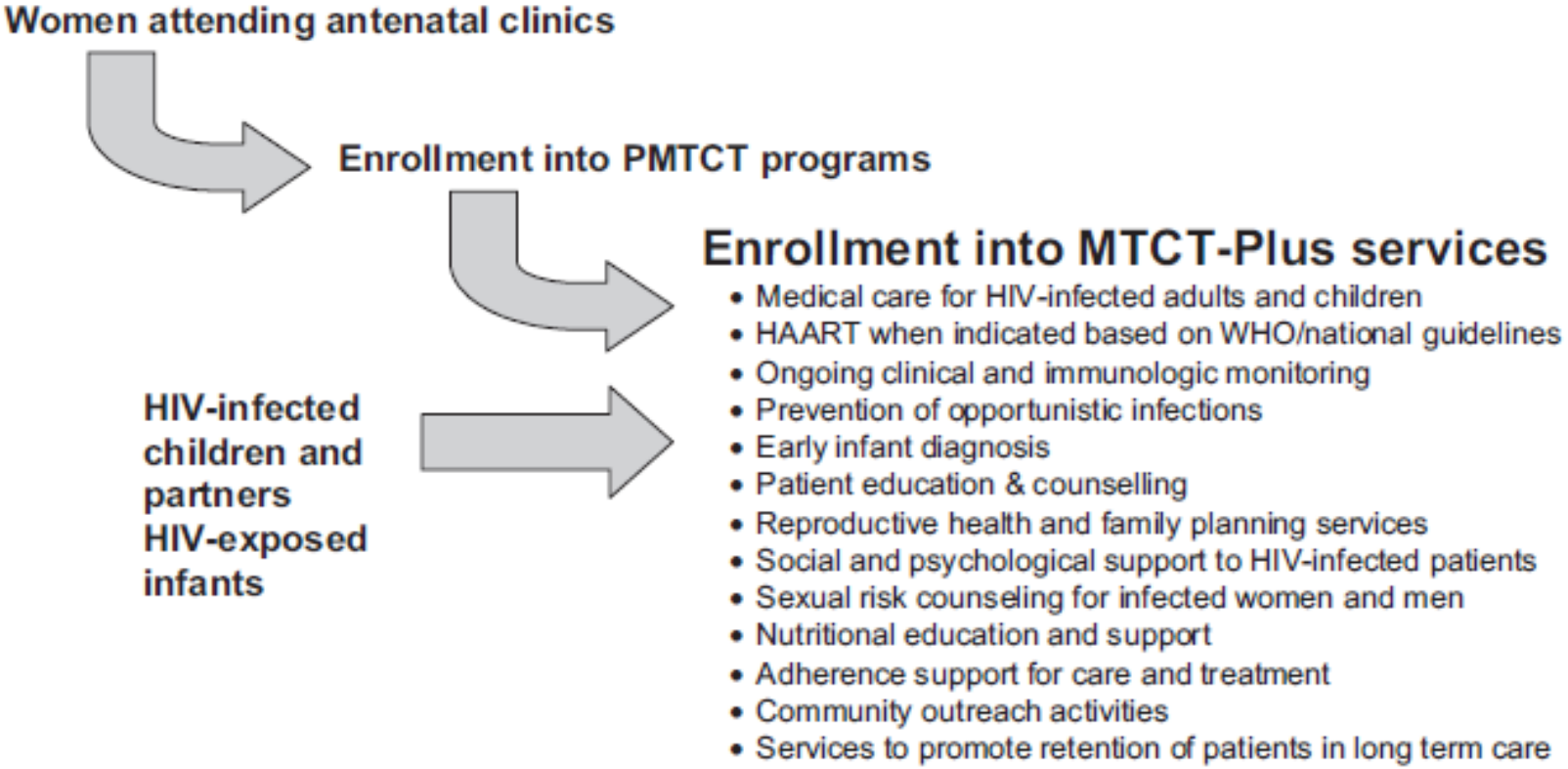
Family-Centered PMTCT plus

- The ‘hallmark’ family-centered program for PMTCT has been the MTCT-plus Initiative (Abrams et al., 2007)
- PMTCT is viewed as an entry point into comprehensive family-focused services for women, their exposed infants and HIV-infected family and household members

MTCT Plus (Abrams 2007)

FIGURE

Enrollment into and services provided by the MTCT-Plus Initiative



Abrams. PMTCT: a gateway to family-focused HIV care and treatment. AJOG 2007.

Other Examples

- Using a family-based approach in rural Uganda , Mermin et al (2005) evaluated several interventions that could form a “preventive care package”
  - Home-based VCT was offered to 6,000 family members of HIV+ and accepted by >95%: 35% of married HIV+ discovered that they were living with an HIV-uninfected spouse;10% of children < 5 had undiagnosed HIV
  - Cotrimoxazole consumption by HIV+ associated with 46% less mortality; 30-70% lower incidence malaria, diarrhea and hospitalization
  - when HIV+ parent took prophylaxis: 63% reduction in mortality among HIV- children (likely because parent death was associated with a 3X increase in mortality)
  - Simple home-based water purification system resulted in 25% reduction in diarrhea among HIV+ individuals

Source: Mermin, 2005

Involving Fathers

Uganda: TASO offered special sessions on Saturdays for HIV testing for men; Other innovations: a novel testing program at the time of delivery, increased uptake of HIV testing among male partners

Ivory Coast: HIV-positive women and infants followed over 2 years of PMTCT project

- –When men knew their wife was HIV positive and were involved in the PMTCT project, they played an active role in applying the advice received
- –particularly related to exclusive breast feeding and early weaning or guidelines for infant formula feeding (Traore et al, 2009)

Family-related factors that can increase access and adherence to PMTCT

- Addressing concerns regarding disclosure of HIV status with family members
- Increasing access to routine HIV testing with the rapid test for all family members (promoted through decentralized access at clinics rather than district hospitals)
- Promoting family support for receiving early antenatal care, delivering at the hospital, and accessing PMTCT
- Integrating PMTCT care with services for all family members (e.g. increasing access to ART, pediatric care, early childhood development support, community health workers, home visiting models, etc.)

  –like idea of family wellness centers with outreach component

Family-Centered PMTCT: Challenges

- There remains a prevailing use of single-dose antiretrovirals to combat MTCT, despite consensus among organizations like UNICEF and WHO that a more holistic approach like PMTCT-Plus is needed (Eyakuze et al., 2008)
- Many PMTCT approaches are underdeveloped
  - programs that counsel mothers on family planning may not distribute methods of family planning
  - Some programs are not equipped to diagnose infants until 18 months of age (Newell et al., 2004)
- No comparative research
  - “Clinical trials on the efficacy of complete family-centered care versus segmented delivery of only ART or PMTCT are virtually non-existent” (DeGennaro and Zeitz, 2009)

What Do We Know about Family-Centered ECD ?

Family-Centered ECD

- It is well known that ECD interventions need to consider the mother's and infant's needs in tandem, rather than a sole focus on the infant
- Family members play a primary role in facilitating their children's interaction with and exposure to environmental stimuli (Richter, 2004)
- Work with larger family system can help address problems such as IPV, MH problems as well as enriching a range of attachment relationships to support healthy child development

Family-Centered ECD

- Evidence indicates that involvement of fathers and extended family can support the mother in providing a nurturing environment; When fathers were included in the ECD plan, there were benefits for the mothers as well as the infants (Magill-Evans et al., 2006)
- Home-based approaches, where community health workers visit families to offer ECD support, reaches out to the most vulnerable families and also shown to benefit the mothers' psychological well-being as well as the quality of their involvement with their infants (Minde et al.,1980)

Family-Centered ECD

Nutrition + ECD intervention in Bogota, Colombia

- Three gps of infants at risk of malnutrition randomly assigned to 1 of 4 experimental groups involving combinations of ECD home visits and food supplementation for the entire family
- Home visiting increased protein intake and father's involvement with the child
- Infants in the ECD + nutrition group had significantly improved nutritional status after three years of follow-up (Super et al., 1990)

Examples of Family-Centered ECD

- **Turkish Early Enrichment Project**
  N=117, children aged 3-5 years

  - Mother training (MT) program consisting of *educational component* (teaching pre-literacy/numeracy skills) and *enrichment program* to support mothers in parenting and spousal roles
  - **By year four**: Children of mother-trained (MT) group exhibited higher cognitive development scores (general achievement test scores, social development and school adjustment scores)
  - **After 10 years**: More children of MT group were in school; had higher GPA, higher vocabulary scores, higher family adjustment scores, and greater self-confidence
  - **In MT group,** *mother's status vis-à-vis her role in the family*, particularly in relation to her husband, was improved

*(Kagitcibasia, Sunarb, & Bekman, 2001)

Examples of Family-Centered ECD

- Roving Caregivers Program (RCP) in Jamaica
  - N=163, children 3-36 months
  - Included home visiting, early stimulation and parenting initiative aimed at promoting development, health and nutrition of children.
  - Parenting practices improved when parents and children were *actively* involved in the home-visiting program (Powell, 2004).
  - Children in the intervention group exhibited significantly higher developmental outcomes than those in control group

Rwanda Learning Collaborative on PMTCT plus ECD

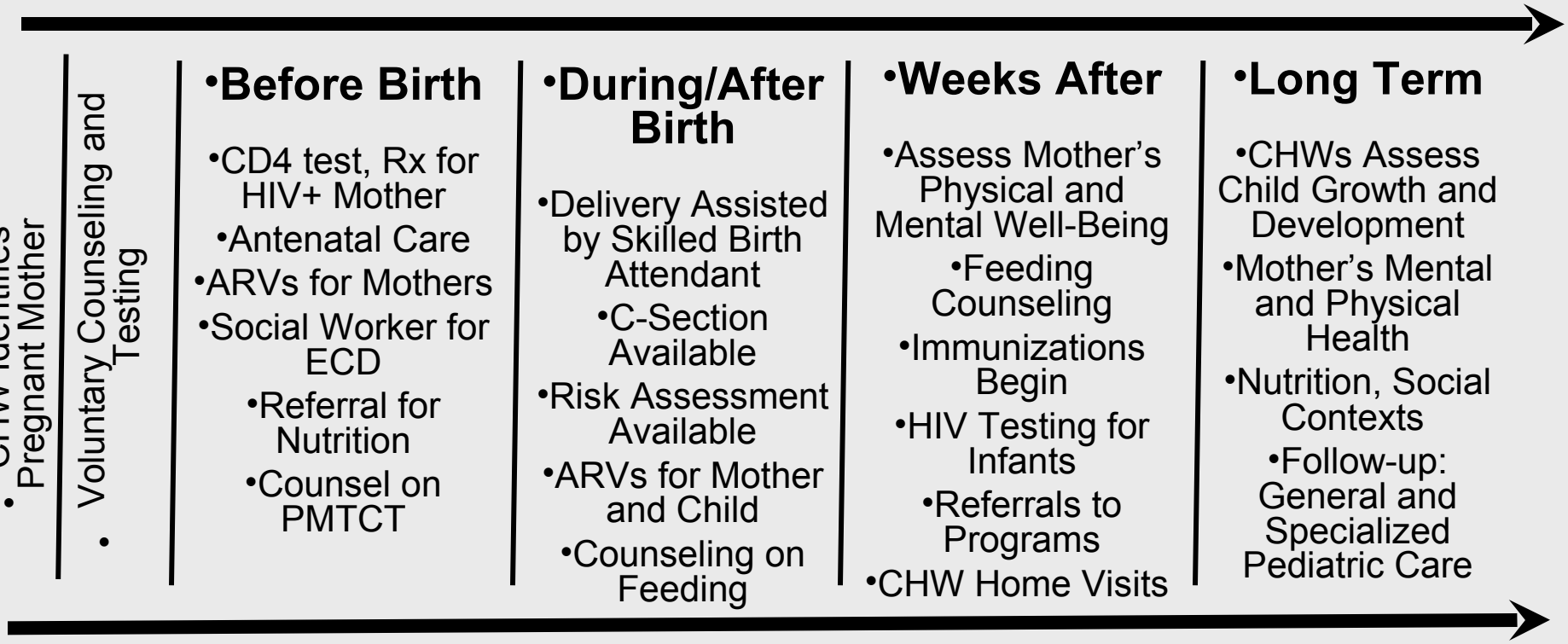
Site Selection: Rwanda

- HIV Prevalence 3%; 10% are infections in children
- PMTCT made a national priority
- Adoption of comprehensive PMTCT services in 2006
- Recent scale up of PMTCT sites
- Decentralized health care model
- Existing Community Health Worker system
- Experience in previous Quality Improvement projects

Rwanda Learning Collaborative Process

- Quality Improvement Methodology: Value Chain analysis, Breakthrough Learning Collaborative Model
- Viewed PMTCT as an entry point for comprehensive family care, including ECD
- Targeted PMTCT Interventions
  - Before birth
  - During and after birth
  - Weeks after
  - Long term
- Early Childhood Development (ECD) services
  - Over the long term
  - Main modality through nurses training of community health workers
  - Need for Family-Centered approach very clear in relation to ability to implement infant feeding recommendations

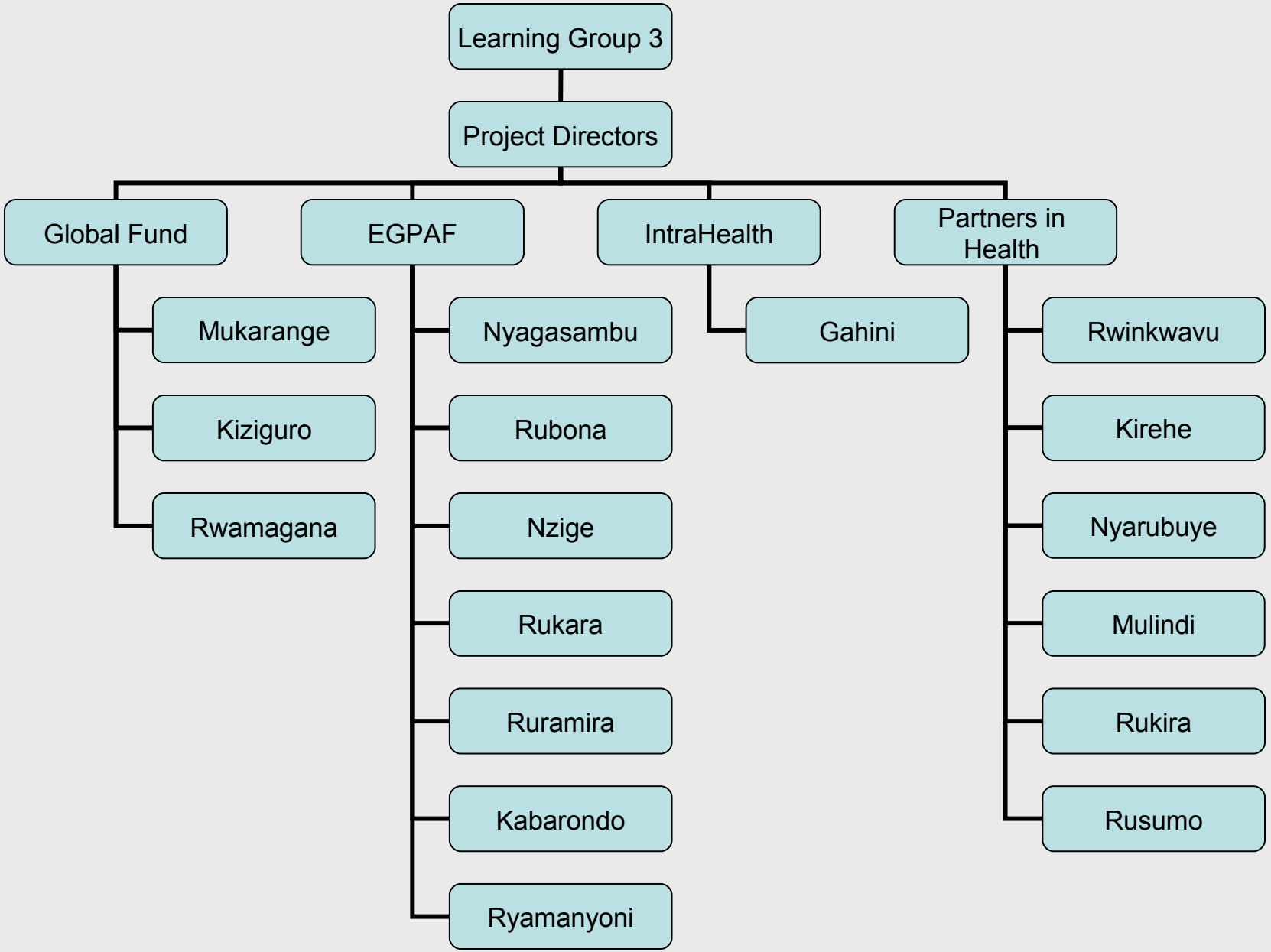
Value Chain


CHW Identifies Pregnant Mother
Voluntary Counseling and Testing
•Before Birth
•CD4 test, Rx for HIV+ Mother
•Antenatal Care
•ARVs for Mothers
•Social Worker for ECD
•Referral for Nutrition
•Counsel on PMTCT
•During/After Birth
•Delivery Assisted by Skilled Birth Attendant
•C-Section Available
•Risk Assessment Available
•ARVs for Mother and Child
•Counseling on Feeding
•Weeks After
•Assess Mother's Physical and Mental Well-Being
•Feeding Counseling
•Immunizations Begin
•HIV Testing for Infants
•Referrals to Programs
•CHW Home Visits
•Long Term
•CHWs Assess Child Growth and Development
•Mother's Mental and Physical Health
•Nutrition, Social Contexts
•Follow-up: General and Specialized Pediatric Care

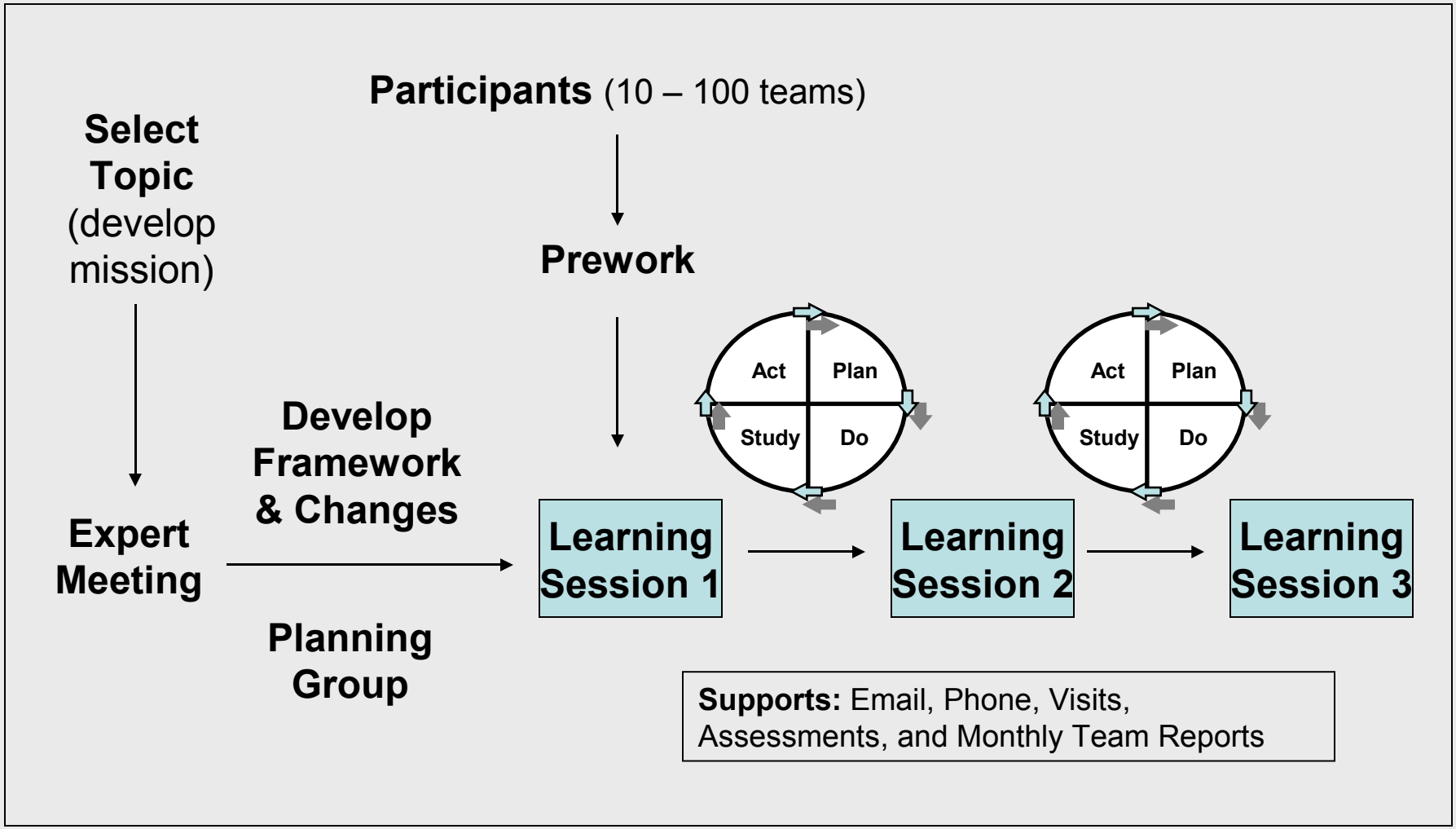
Learning Collaborative Objectives

- 90% of all women in the district will have access to prenatal/PMTCT services
- 95% of women identified with HIV will be started on an ARV regimen in accordance with Rwanda's TRAC guidelines
- 95% of infants at risk for transmission of HIV will be supported with a feeding method that will reduce the risk of HIV transmission through feeding
- 95% of all infants needing cotrimoxazole prophylaxis will receive medication
- 95% of infants identified will receive three visits in 6 months to ensure appropriate early childhood development
- 95% of all infants identified will receive bed nets for malaria prophylaxis
- 95% of all infants will have access to full immunization programs

Learning Collaborative Organizational Structure



Breakthrough Series Collaborative Model



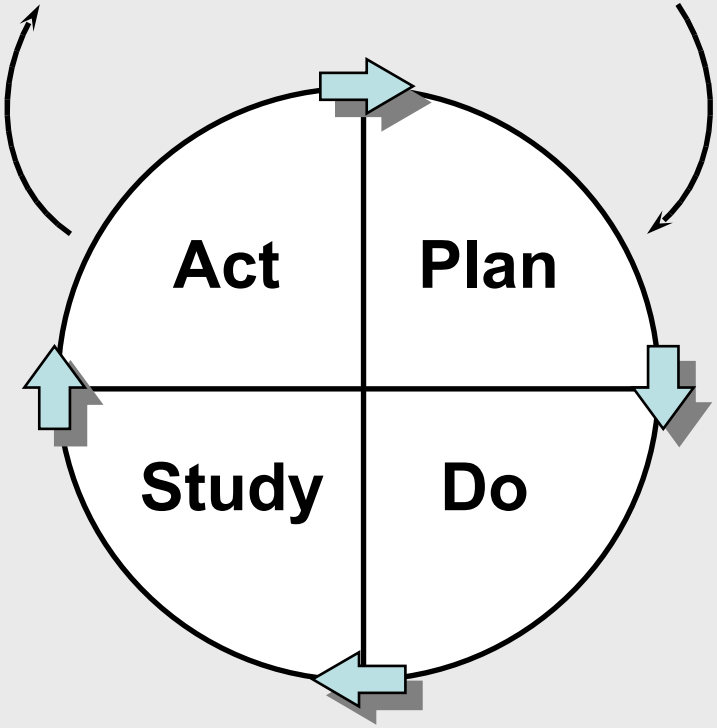
Source: Institute for Healthcare Improvement (IHI) 2003

Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

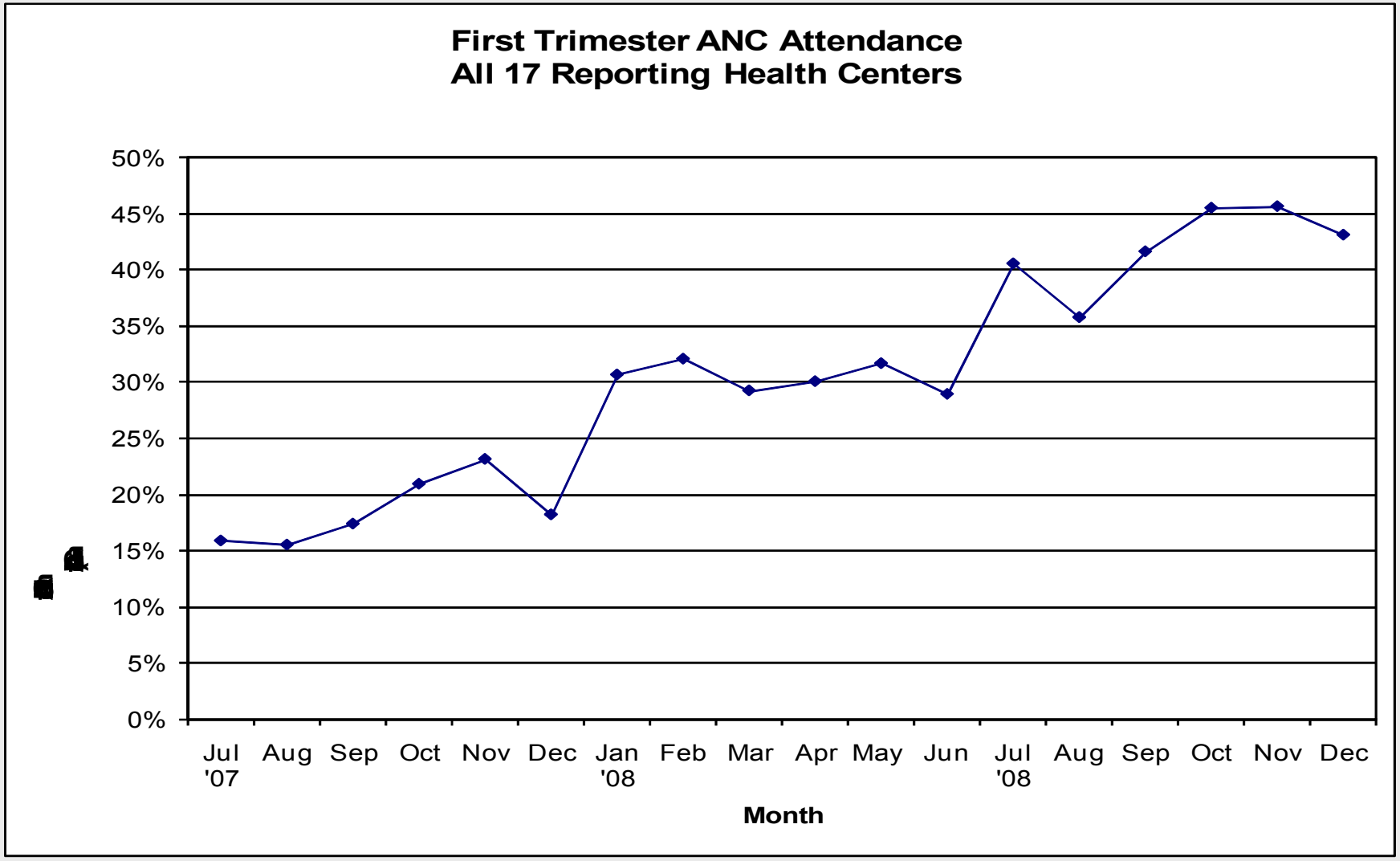
What change can we make that will result in improvement?



Reaching Objectives Using PDSAs

- Objective: 90% of all women in the district will have access to prenatal/PMTCT services
- Intervention to reach objective: Increase Prenatal Care Attendance (entry point into PMTCT services)
- PDSA Examples
  - Rubona: provided incentives to women (umbrellas)
  - Mukarange: provided cash incentives to Community Health Workers (CHWs)
  - Kirehe: provided transportation reimbursements to women
- Incentives offered to women in particular were found to promote access to prenatal care in first trimester

Data Collection



Early Childhood Development

- Objective: 95% of infants identified will receive three visits in 6 months to ensure appropriate early childhood development (ECD) supports

- Determined need for ECD monitoring
  - Existing screening was insufficient
    - Growth monitoring
    - Weight for Age

No assessment of age appropriate physical, social or mental development

Developed ECD Tool

- Review of existing tools
  - PEDS, Denver II, Ages and Stages
- Integrated Management for Childhood Illness (IMCI) Care for Development module
  - *Counsel the Mother*
  - Greater focus on counseling
- Developmental Screening questions
  - USAID-Academy for Educational Development Program “Speak for the Child”

ECD Tool

ECD at up to 4 months	
ASK THE MOTHER:	
1. Does your child follow people and objects with his or her eyes?	Y ☐ N ☐

ECD at up to 4 months

ASK THE MOTHER:

DEVELOPMENT:

FEEDING FOR HIV EXPOSED CHILDREN:

1. Breastfeed exclusively

OR (if feasible and safe) –

2. Formula feed exclusively

Do <u>not</u> give your child foods or any other fluids.

1. Breastfeed exclusively as often as the child wants, day and night. Feed at least 8 times in 24 hours, or every 3 hours. **Breastfeed** when the child shows signs of hunger: begins to fuss, sucks fingers, or moves his or her lips.

Prepare to stop breastfeeding at 6 months if AFASS according to national guidelines.

2. Formula feed exclusively. Prepare correct strength and amount just before use. Use milk within an hour and discard any leftover. Use a cup for feeding (or a bottle if provided by the feeding program).
Clean the cup and utensils with soap and water. Feed your child 6 to 8 times per day.

Imikurire y'umwana ukivuka kugeza ku mezi 4

BAZA UMUBYEYI:

IMIKURIRE:

IMIRIRE IKWIYE KU BANA BASHOBORA KWANDURA SIDA:

1. Amashereka yonyine
– CYANGWA (niba hari ubushobozi buhagije bikaba bifitiwe isuku) -
2. Amata y'insimburamashereka yonyine

Ntukagire ibindi biribwa cyangwa ibinyobwa uha umwana wawe

1. Ha umwana amashereka yonyine mu gihe cyose abishaka, haba ku manywa ndetse na nijoro. Ujye umugaburira byibura inshuro 8 mu masaha 24 cyangwa buri masaha 3. Ujye wonsa umwana mu gihe agaragaza ko ashonje : nk'iyo atangiye kurira, konka intoki cyangwa kunyeganyeza iminwa.

Witegure guhagarika konsa konyine mu gihe umwana agejeje amezi 6 niba wujuje ibyangombwa bisabwa (AFAD) ukurikije uko amabwiriza y'igihugu abiteganya.

2. Kumuha amata y'insimburamashereka.
Ubanze uyategure ku gipimo gikwiye mbere y'uko uyamuha. Ushobora kongera gukoresha ayo mata mu isaha ikurikira hanyuma asigaye ukayamena. Koresha agakombe uyamuha (cyangwa agacupa niba ari ko bitaganywa na gahunda y'imirire).
Koresha amazi n'isabune **usukura** agakombe n'ibindi bikoresho.Ugaburire umwana kuva ku nshuro 6 kugeza ku nshuro 8 ku munsi.

Need for Family-Centered Approach

- Major barrier to weaning @ 6 months identified by mothers & nurses was lack of appropriate replacement foods
- feeding recommendations could not be implemented without nutritional support
- RLC provided SOSOMA (sorghum+soya+maize)
- Increased clinic attendance for other services as well

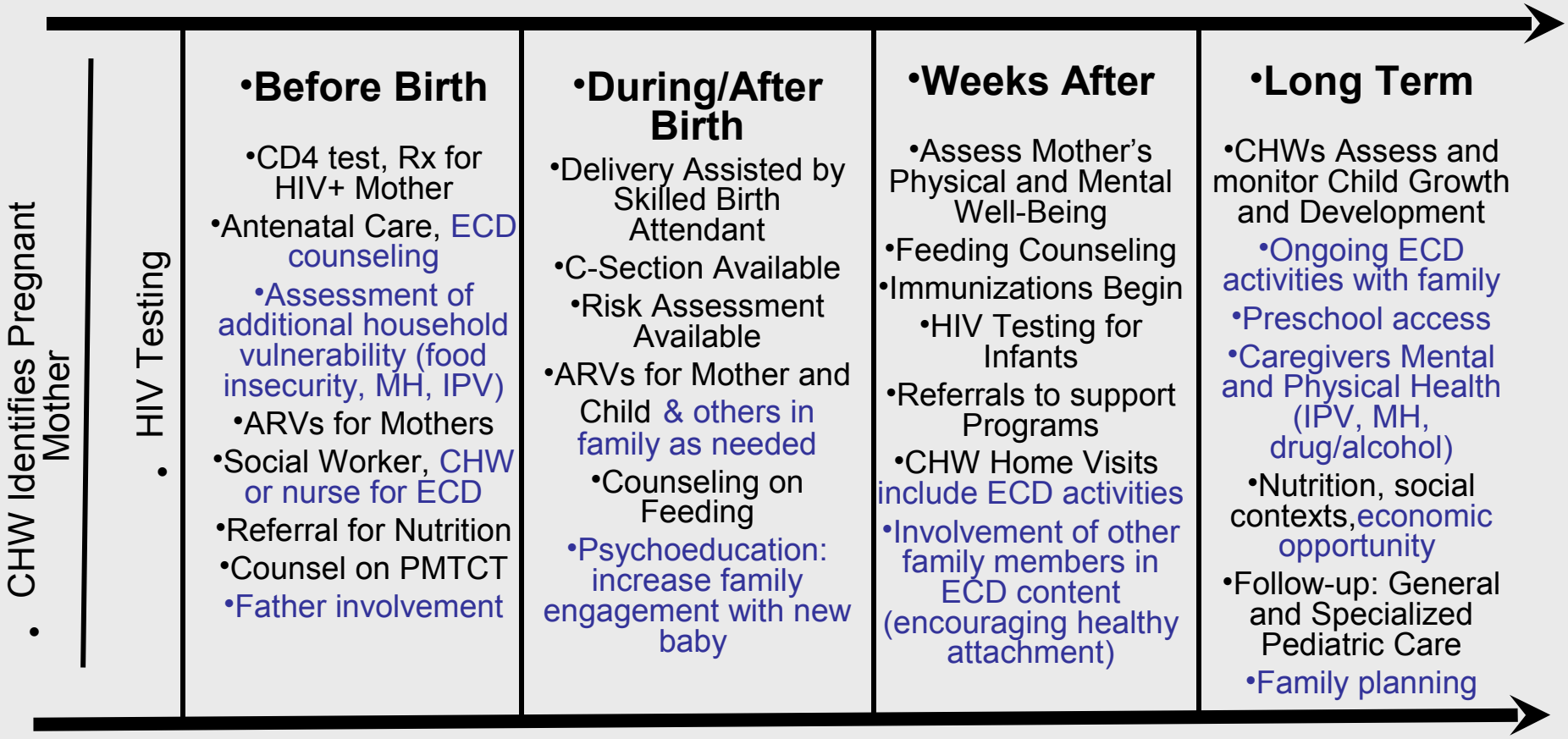
Future Plans

- Project activities ended in March 2009
- Potential for further development of the model and materials
- Continue to gather feedback on training and implementation of tool
  - Focus groups
  - Observe Quality and Content of CHW counseling
- Incorporate ECD training into CHW training curriculum
  - At additional MoH health centers
  - At PIH Health Centers (via nutrition training)

Much to do..

- JLICA Learning Collaborative gives a glimpse of issues to be expected
- Combining Family-centered PMTCT and ECD services has great potential
- Likely to improve outcomes of both the PMTCT and ECD engagement and efficacy

Towards an Integrated family strengthening approach to PMTCT plus & ECD



Conclusions

- PMTCT Plus is an entry point for improving overall family health and functioning
- ECD can be integrated along the PMTCT value chain with nutrition, primary health care, and other family-based healthcare programs
- Family-centered approaches are critical for both PMTCT and ECD and their effective integration
- Strategies for crossing the implementation gap are critical next steps

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Thank you!

Examples of Family-Centered ECD

- Integrated Family-Based ECD (IFBECD) Thailand
  - Since 1990 operates out of child health centers and involves collaboration between mothers (who volunteer as ambassadors), the health center system, and the broader community (e.g., NGOs).
  - Each ambassador works with 5 families in her neighborhood and provides the mothers with information and advice about child health, nutrition, and development

- **Results**: After 2 years of intervention, there were improvements in nutritional status, developmental performance, and IQ scores of children, as well as more positive parental attitude and involvement (Kotchabhakdi, 1999)