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BASICS PEDIATRIC HIV TOOLKIT

**TAKING EVERY OPPORTUNITY:
ENSURING INFANT ACCESS TO
EARLY HIV DIAGNOSIS, CARE
AND TREATMENT**



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Taking Every Opportunity: Ensuring Infant Access to Early HIV Diagnosis, Care and Treatment



Global Health Council Conference Panel

Saving Infants:

PMTCT, Postnatal Care and Early Pediatric HIV Interventions

29 May 2008

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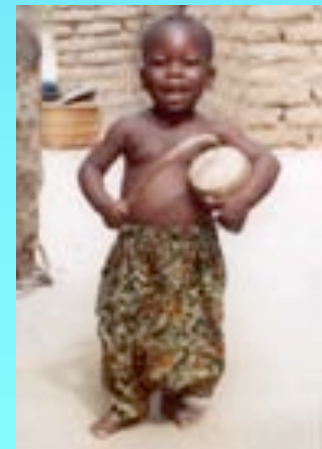
Imagine

We have been sitting listening to presentations for a few minutes. I am on my 10th slide.

Suddenly there is an eruption of noise and in march 100 children under 5, the older ones carrying the babies. They have signs and banners and songs and are demonstrating for greater access to HIV care and treatment services.

Groups of “grown ups” have demonstrated at AIDS conferences for over a decade.

Whenever I put on my “under five with HIV lens” I wonder if someone shouldn’t be marching.



OVERVIEW

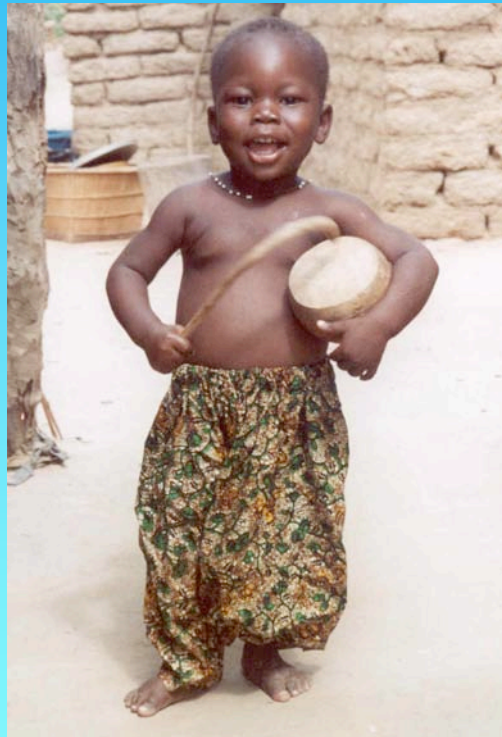
- Background
- HIV disease in infants
- Early diagnosis, treatment and elements of essential care
- Pathway to care and missed opportunities
- Insights from the field, findings and recommended action steps



What would the public health community do if a study came out tomorrow providing evidence that a large proportion of adults with HIV had only a few months to live without treatment?



BACKGROUND



How do most infants become infected with HIV?

95% of HIV transmission to infants occurs during pregnancy, labor, delivery or breastfeeding.

This is referred to as mother to child transmission or **MTCT**.
The prevention of MTCT is referred to as **PMTCT**.

Children and HIV

Global Estimates 2007

- **Number of children living with HIV and/or AIDS**
 - **2.1 million** [1.9 million – 2.4 million] **children younger than 15 years of age**
 - **~ 90% in sub-Saharan Africa**
- **Number of children newly infected (2007)**
 - **420,000 children** (of 4.1 million total)
- **Globally, 1200 HIV-infected infants are born daily**
- **Number of children who died of AIDS (2007)**
 - **290,000 children** (of 2.4 million total)

Contrasts in Program Coverage: PMTCT and Immunization

- **In 2006**
~ **23 percent** of pregnant women with HIV in low- and middle-income countries accessed antiretroviral prophylaxis to prevent MTCT transmission.

UNICEF/UNAIDS/WHO.
Children and AIDS: a stocktaking report. 2008

- **70% of all children** reached with routine immunization with vaccines (DPT) each year since 1990.

UNICEF, 2005



HIV Disease in Infants

HIV Testing in Infants

- **Until an infant is about 15 months or older HIV antibody test detects maternal antibodies -- does not tell if infant is infected with HIV.**
- **The infant excretes most of the maternal antibodies by about 9 to 15 months unless the infant is breastfeeding.**

- **Must repeat virological tests after 6 weeks if the infant is breastfed and the first test is negative.**
- **One positive virological test at 4-8 weeks is sufficient to diagnose infection in a young infants.**

HIV Disease Progression in Infants and Children

HIV disease progression is MORE RAPID
in infants and children than in adults.

- Children have immature (but developing) immune systems---disease progression is rapid and each clinical disease stage is shorter.
- The usual lab measures of immune system function are not as clearly correlated with symptoms in young infants as in adults.

- **Immature immune system
+
immune system destruction =
overwhelming bacterial infections.**
- **Common childhood infections and conditions
more frequent and more fatal in children with HIV.**
- **Without treatment, 50% of HIV infected infants will
die before their second birthday.**

Some reports and clinical experience indicate that children perinatally infected with HIV fit into one of three categories:

- 1. Rapid progressors, who die by age 1 and are thought to have acquired the infection *in utero* or during the early perinatal period (about 25–30%)**
- 2. Children who develop symptoms early in life, followed by a downhill course and death by age 3 to 5 (about 50–60%)**
- 3. Long-term survivors, who live beyond age 8 (about 5–25%)**

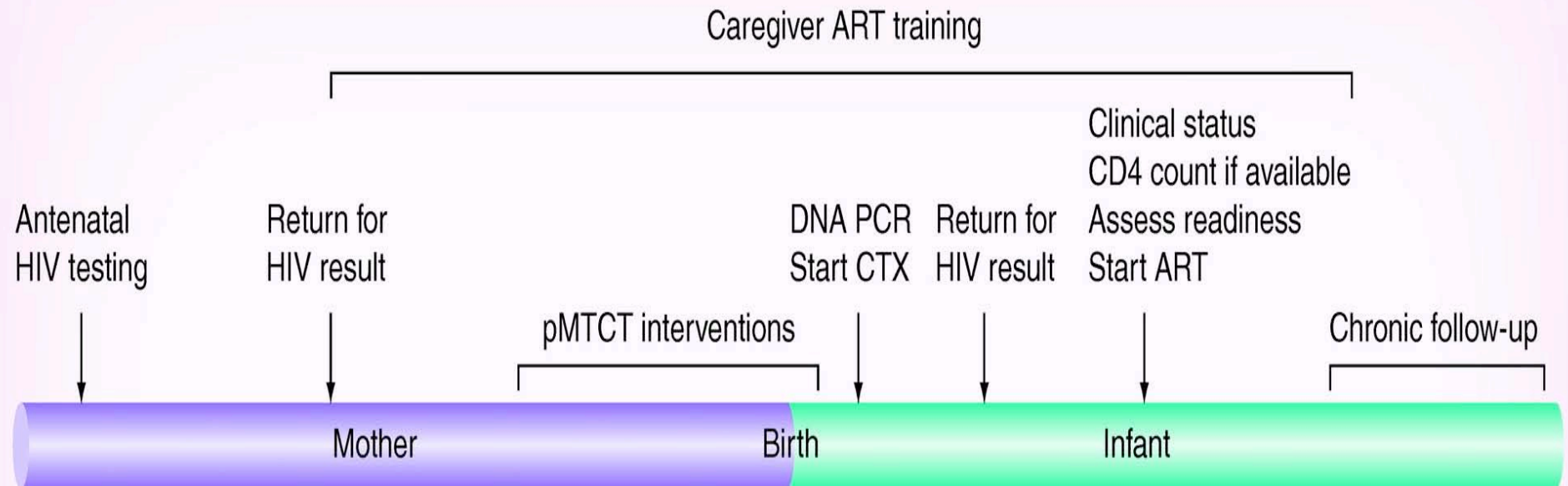


Early Diagnosis and Treatment and Elements of Essential Care

**Recent Studies and Data
and Implications for
Pediatric HIV Programming Action**

Maternal-Infant Pathway to Early Diagnosis and Treatment

Maternal–infant pathway to early diagnosis and treatment



- Current barriers***
- Present coverage insufficient
 - Loss to follow-up
 - Stigma, fear, perceived lack of interventions
 - Present coverage \pm 16%
 - Basic pMTCT regimens (e.g., sd-NVP) less efficacious
 - PCR unavailable in some settings
 - Technically difficult, expensive
 - May have long turn-around time
 - Loss to follow-up
 - Stigma, fear, perceived lack of interventions
 - Few pediatric formulations available or palatable
 - Reluctance to start infants on ART
 - Adherence challenging (and maybe more so in asymptomatic infants)
 - Long-term follow-up difficult

Early Infant Diagnosis (EID)

- **Early diagnosis of HIV in infants is essential.**
- **DBS PCR - transport specimens from lower level to tertiary site with PCR is one approach to this challenge.**



Evidence:

Importance of early ART Initiation in Infants

Meta-analysis of 210 infants from 11 European countries: 80% reduction in clinical progression to AIDS or death among infants treated **before**, compared with **after**, a pre-determined age of **3 months**.

Goetghebuer T, Haelterman E, Le Chenadec J et al.: Presented at: 4th Dominique Dormont International Conference: Host-Pathogen Interactions in Chronic Infections. Paris, France, 13–15 December 2007 (Abstract O25).

Randomized controlled trial in South Africa demonstrated that **starting ART before 12 weeks of age reduces early mortality by 75%**.

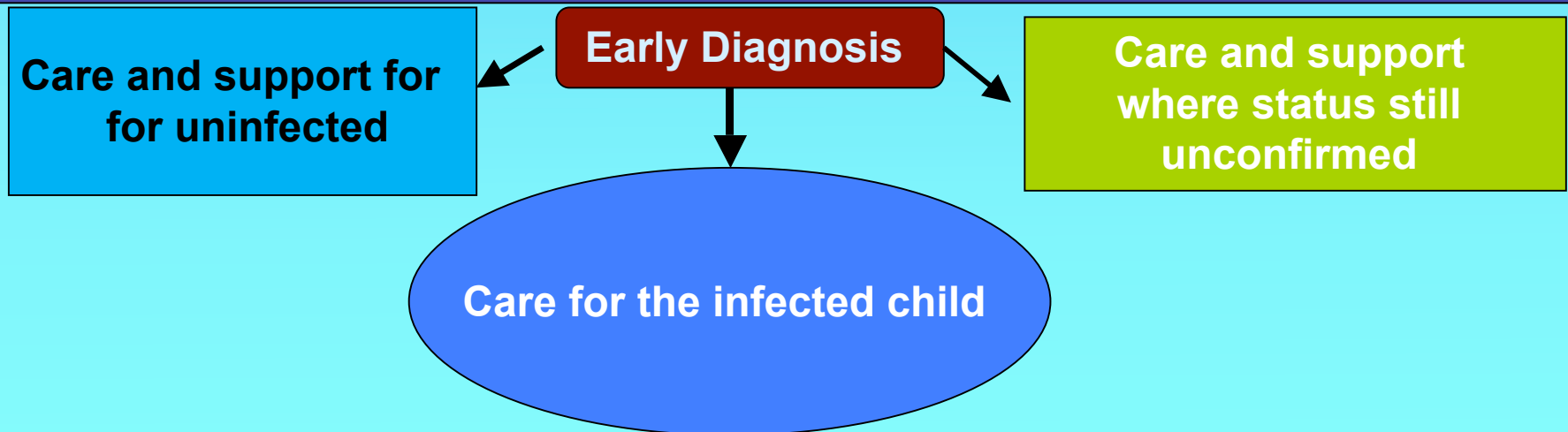
Violari A, Cotton M, Givv D et al. Antiretroviral therapy initiated before 12 weeks of age reduces early mortality in young HIV-infected infants: evidence from the Children with HIV Early Antiretroviral Therapy (CHER) Study. Presentation at IAS meeting

Early ART at Age <3-12 Months is Associated with No AIDS Progression and Maintenance of Immune Reconstitution

Study	N	Age Start HAART	Viral Response	Other
Belgium <i>Van der Linden PIDJ 2007</i>	17	<2.5 mos	<50, 71% at 4.7 yrs	<ul style="list-style-type: none"> ▪ No AIDS ▪ 82% CD4 >25%
PACTG 356 <i>Luzuriaga NEJM 2004</i>	25	<3 mos (median 2 mos)	<400, 60% at 4 yrs	<ul style="list-style-type: none"> ▪ No AIDS, 4 yr
PENTA 7 <i>PENTA AIDS 2004</i>	20	<5 mos (median 2.5 mos)	<400, 44% at 1.5 yrs	<ul style="list-style-type: none"> ▪ No AIDS, 1.5 yr ▪ 90% CD4 >25%
Italian Register <i>Chiappini AIDS 2006</i>	30	<6 mos (median 3.6 mos)	Undetect 73% at 4 yrs	<ul style="list-style-type: none"> ▪ No AIDS, 4 yr ▪ 97% CD4 >25%
PACTG 1030 <i>Chadwick AIDS 2008</i>	21	<6 mos (median 3.7 mos)	<400, 53% at 6 mos	
French Perinatal <i>Faye PIDJ 2002</i>	31	<12 mos (median 3.7 mos)	<500, 18% at 2 yrs	<ul style="list-style-type: none"> ▪ No AIDS, 2 yr ▪ 88% CD4 >25%

CARE TREATMENT AND SUPPORT FOR ALL HIV EXPOSED

- Early diagnostic testing for HIV infection
- Infant feeding counselling and support
- Cotrimoxazole prophylaxis
- Assessment, management and follow up of common conditions
- Regular growth monitoring, developmental assessment & support
- Immunization
- Prevention, screening and management of tuberculosis
- Prevention and treatment of malaria





- **Co-trimoxazole preventive therapy (CPT) reduces incidence and severity of opportunistic infections such as pneumonia due to *p. jiroveci* (formerly PCP), common bacterial infections, toxoplasmosis and malaria.**
- **Zambia study showed 45% reduction in mortality among HIV infected children who received co-trimoxazole prophylaxis regardless of CD4 count (Lancet 2004).**

Cotrimoxazole coverage



- Only **4% of the estimated 4 million HIV exposed and HIV infected children** who need co-trimoxazole preventive treatment are currently receiving it

Towards universal access: scaling up priority interventions in the health sector. Progress report 2007. Geneva, World Health Organization, 2007



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- **Globally, only 7%** of people receiving ART by the end of 2005 were children.
- Most of the children on ART are older children who can be treated more similarly to adults.

World Health Organisation.

Progress on global access to HIV antiretroviral therapy: a report on “3 by 5” and beyond. March 2006.

Estimated need for ART in Children, 2006

Regions

No. of children needing ART

East and Southern Africa

411,426

West and Central Africa

161,430

572,856

East Asia and the Pacific

14,069

South Asia

29,292

Middle East and North Africa

8,925

**Central and Eastern Europe
and the Caucasus**

426

**Central and South America
and the Caribbean**

19,887

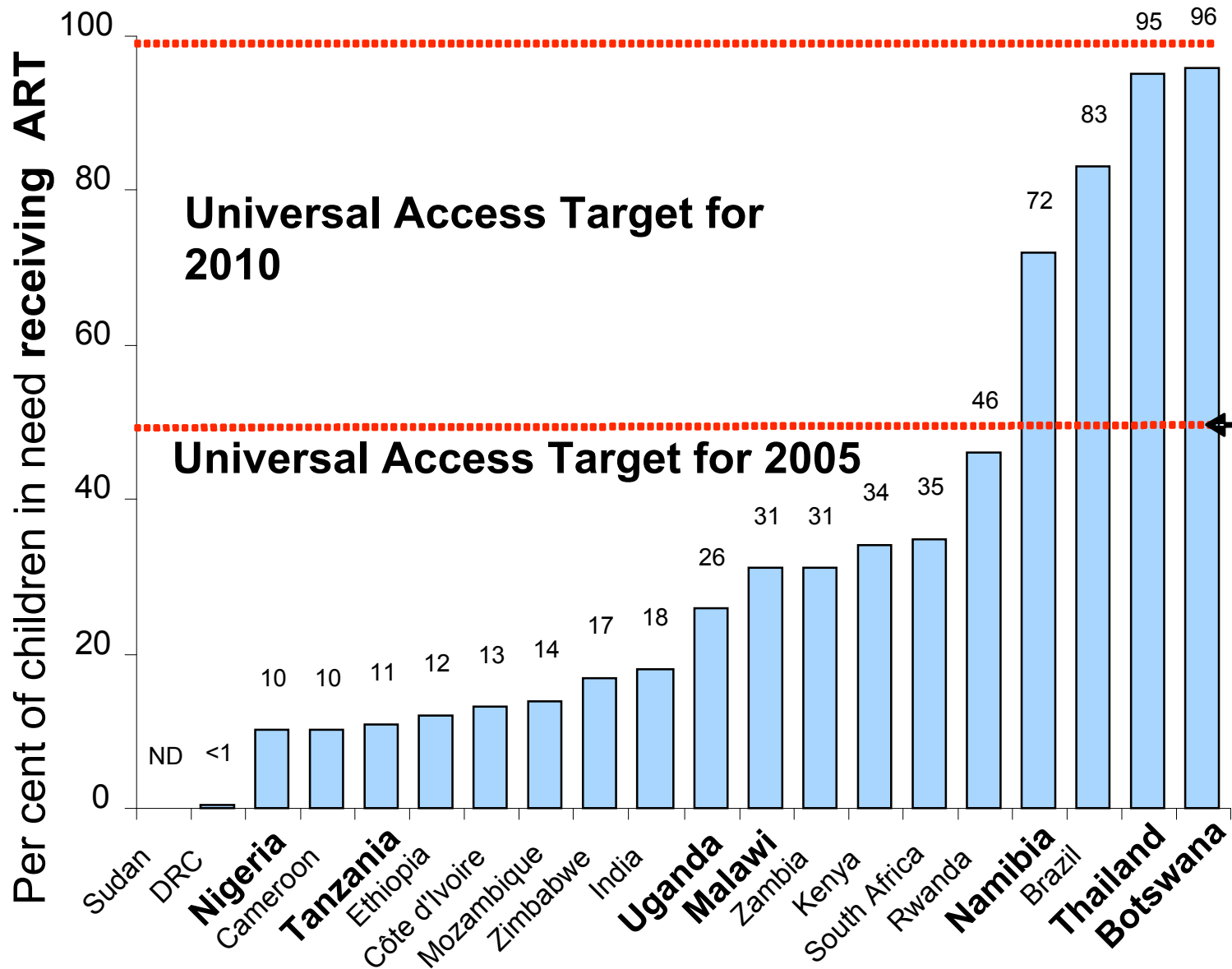
Total Surveyed countries

638,334 (99%)

**All Low and
Middle Income Countries**

646,857

ART coverage



Halfway towards Universal Treatment access for children under 15

Where to Go From Here?

Insights from the Field and Program Approaches

GOAL:

Improve the access of HIV-exposed and infected infants and children to HIV care and treatment





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Pathway to care and missed opportunities



PATHWAY TO CARE

Identification of HIV-exposed infants and children

**Basic care package (including CPT)
Referral for clinical assessment and testing**

HIV serostatus and clinical staging

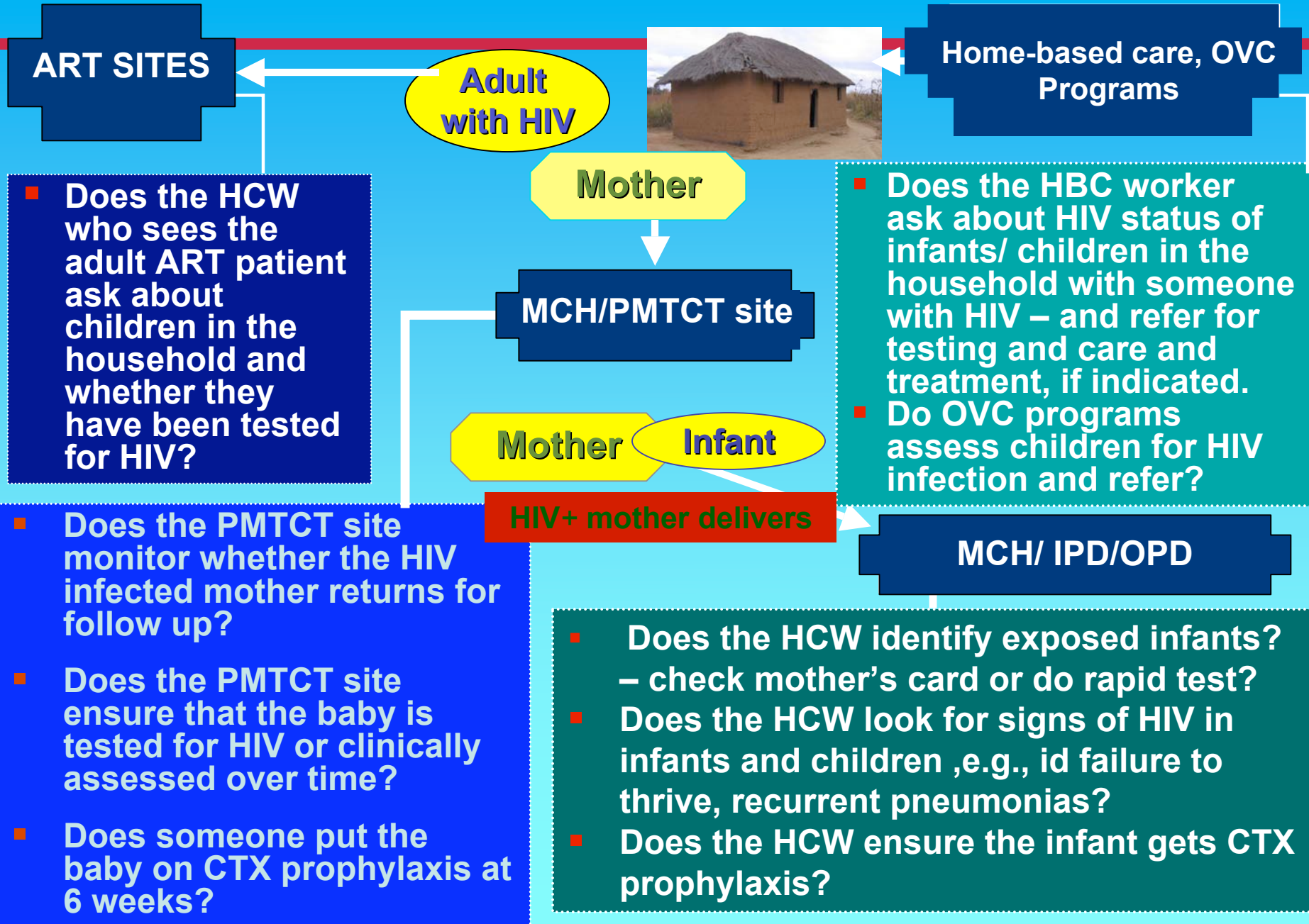
**OI management and/or ART,
continuing Basic Care Package,
palliative care**

Monitoring, follow-up, adherence and other support

Key Issues

- ✓ When and where to refer ?
- ✓ Who gets there and who doesn't and who knows?
- ✓ Who does what if they don't make it?

Missed Opportunities for Pediatric HIV: Program Checklist



ART SITES

Adult with HIV



Home-based care, OVC Programs

- Does the HCW who sees the adult ART patient ask about children in the household and whether they have been tested for HIV?

Mother

MCH/PMTCT site

- Does the HBC worker ask about HIV status of infants/ children in the household with someone with HIV – and refer for testing and care and treatment, if indicated.
- Do OVC programs assess children for HIV infection and refer?

Mother **Infant**

HIV+ mother delivers

MCH/ IPD/OPD

- Does the PMTCT site monitor whether the HIV infected mother returns for follow up?
- Does the PMTCT site ensure that the baby is tested for HIV or clinically assessed over time?
- Does someone put the baby on CTX prophylaxis at 6 weeks?

- Does the HCW identify exposed infants? – check mother’s card or do rapid test?
- Does the HCW look for signs of HIV in infants and children ,e.g., id failure to thrive, recurrent pneumonias?
- Does the HCW ensure the infant gets CTX prophylaxis?

Challenge: finding children under five with HIV

In seeking to find and care for infants and children with HIV, early in the course of their HIV disease, we must ask ourselves “where can we find large numbers of children under 18 months old who might be HIV infected?”

One answer:

UNICEF reports that in 2003, 94% of one years olds were immunized against measles in Swaziland, 70% in Lesotho, and 97% in Tanzania.

MCH clinics and other sites hold promise.



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Insights from the field, findings and recommended action steps



Men's PLHA support group - session findings

- 90 minute interview session with sixteen men in a PLHA support group
- When asked, learned that between them there are about 20 last born children (1 month old - 16 years old).
- Their wives know their HIV status and most used PMTCT services (no details asked about ART prophylaxis, etc.)
- When asked how many of their children had been tested for HIV, there was only one man and he had had two of his children tested – one was negative and he is awaiting results for recently born child.
- Reasons given for not having children tested:
“It is hard even for us to admit we have HIV so it is hard to think of a child with HIV.”
Also, mentioned the distance to get the test.

“What is the community’s attitude are about getting a child tested for HIV?”

Selected Responses –

~15 members of village health committee in rural area

- If positive, would make people “see my family as promiscuous.”
- Belief that children cannot get the virus.
- “Most feel child will die”



Up to 85% of HIV-exposed infants are lost to follow-up from clinics providing services for preventing mother-to-child transmission at **1 year of age**

75–80% already lost to follow-up at 6 months of age

(South African example of impact of no system in place for f/u)

Patton J et al. Evaluation of Dried Whole Blood Spots Obtained by Heel or Finger Stick as an Alternative to Venous Blood for Diagnosis of Human Immunodeficiency Virus Type 1 Infection in Vertically Exposed Infants in the Routine Diagnostic Laboratory. *Clinical and Vaccine Immunology*, February 2007, Vol. 14, No. 2.

PMTCT Follow Up Testing

	Per centage of infants born to HIV + mothers tested within 12 months of birth	Per centage of infants born to HIV + mothers tested within 2 months of birth
East and Southern Africa	1	<1
West and Central Africa	1	<1
East Asia and the Pacific	7	<1
C. & S. America and the Caribbean	30	14
C. & E. Europe and the Caucuses	11	4
South Asia	<1	<1
Middle East and N. Africa	1	<1
All Low and Middle Income Countries	2	1

Assessment Findings

Selected findings from several African countries

- HIV testing, CPT provision, ART initiation require that mothers move about the facilities with their infants --- not integrated yet into most MCH services.
= *poor utilization of ANC and child health services*
- Maternity discharge summary and peds inpatient records do not document mother's HIV status.
- HIV testing guidelines are geared towards child protection rather than infant access to care and treatment.

- **Lack of community education and mobilization.**
- **Provider discomfort about testing or treating infants.**
- **Lack of national advocacy around operational aspects of pediatric HIV.**
 - *Reaching ART targets gets highest priority*
- **More effort placed on ART than on all the steps to get there, e.g., referral systems, community mobilization.**



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Recommended Action Steps



ACTION STEPS

- **Expand the use of all entry points to test infants and children – beyond just PMTCT**
- **Use the child health platform - find the children where they are, e.g., at home, at immunization visits, through OVC programs, HBC programs.**
 - Introduce detailed guidelines for counseling testing infants and children in OPD, IPD, MCH
 - Use HIV positive parents as entry points to find exposed infants and children
 - Link RCH, PMTCT, ART, and HBC programs through referral systems, training, etc.

HIV-EXPOSED INFANTS

- **Strengthen infant follow up**
 - ✓ **Mother-infant cards**
 - ✓ **Expanded PMTCT coverage**
 - ✓ **Links from the facility to the community**
 - ✓ **CHW coverage for home delivery f/u**
 - ✓ **Introduce or pilot early virological HIV testing at 6 weeks wherever possible (including using DBS)**
 - ✓ **Introduce earlier antibody testing (9-12 months)**
 - ✓ **Institutionalize Co-trimoxazole prophylaxis as early as possible (4-6 weeks)**

HIV-INFECTED INFANTS

■ Improve postnatal care

- Early identification of rapid progressors – treat early, reduce mortality
- Support of feeding choice (ideally addressed at ANC) from an early stage

Keep infant and mother alive to protect the investment in PMTCT and ANC care and treatment

- **Establish policy of a post partum follow up visit within 3 days of delivery (ideal) with f/u at 2, 4/6 weeks.**
- **Support existing use of DBS-PCR and expansion where feasible.**
- **Integrate pediatric HIV activities into regional and district health plans.**

Recommended Action Steps, cont'd.

- Use NGOs, CBOs or CHWs to follow up mothers in the community after delivery automatically or at least when there is a no-show within x no. of weeks post partum.

- Expand IMCI-HIV



- **Train all providers who encounter infants and children (MCH, peds inpatient)**
- **Support mother to mother groups.**
- **Use a PHASED approach --- scale up early identification, testing, CPT, etc. while expanding PMTCT and ART services.**
- **Educate parents and communities – address fear, stigma, access issues**



Think again about the marching children

They ask us to figure this all out and to stop saying

“It is expensive to treat babies...those formulations are complicated and expensive....”

“Diagnosis is so complicated in children.”

“People don’t want to treat them....doctors are scared of babies.”

“We should really focus on prevention more.....it’s cheaper and more effective.”

They ask to remember that they also suffer when they have HIV, they are waiting - they have no ACT UP kids group and many don’t have long to live.



**What should the public health community do now that we know many infants with HIV (infected at birth) will die if they do not receive treatment within the first few months of birth?
And do we have the will to do it?**



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