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Providing Treatment, Restoring Hope

**Obstacles to caring for children with HIV
We can do better?**

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AIDSRelief Deputy Chief of Party for Africa*

Presentation for the CRS OVC Forum
Washington June 26, 2008





- Pediatric HIV burden of disease**
- Barriers to entry into care**
- Characteristics of pediatric HIV infection**
- Success to date**
- Examples of treatment**
- New initiatives**

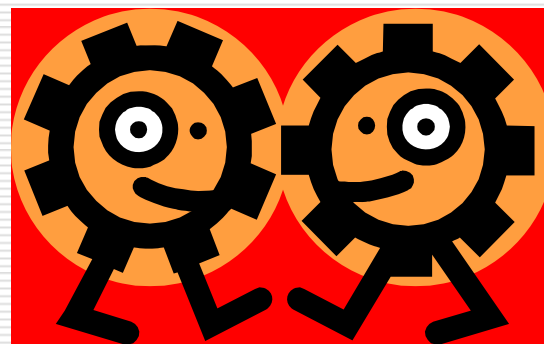


- ❑ 33.2 million people infected
- ❑ **2.5 million** children < 15 years
- ❑ 2.5 million people newly infected in 2007
- ❑ **420,000** children newly infected in 2007
- ❑ **50%** of HIV+ children die before 5 years of age, if no interventions given
- ❑ The majority of HIV positive cases are in sub-Saharan Africa
- ❑ **15 million** orphans from AIDS



95% MTCT

Others

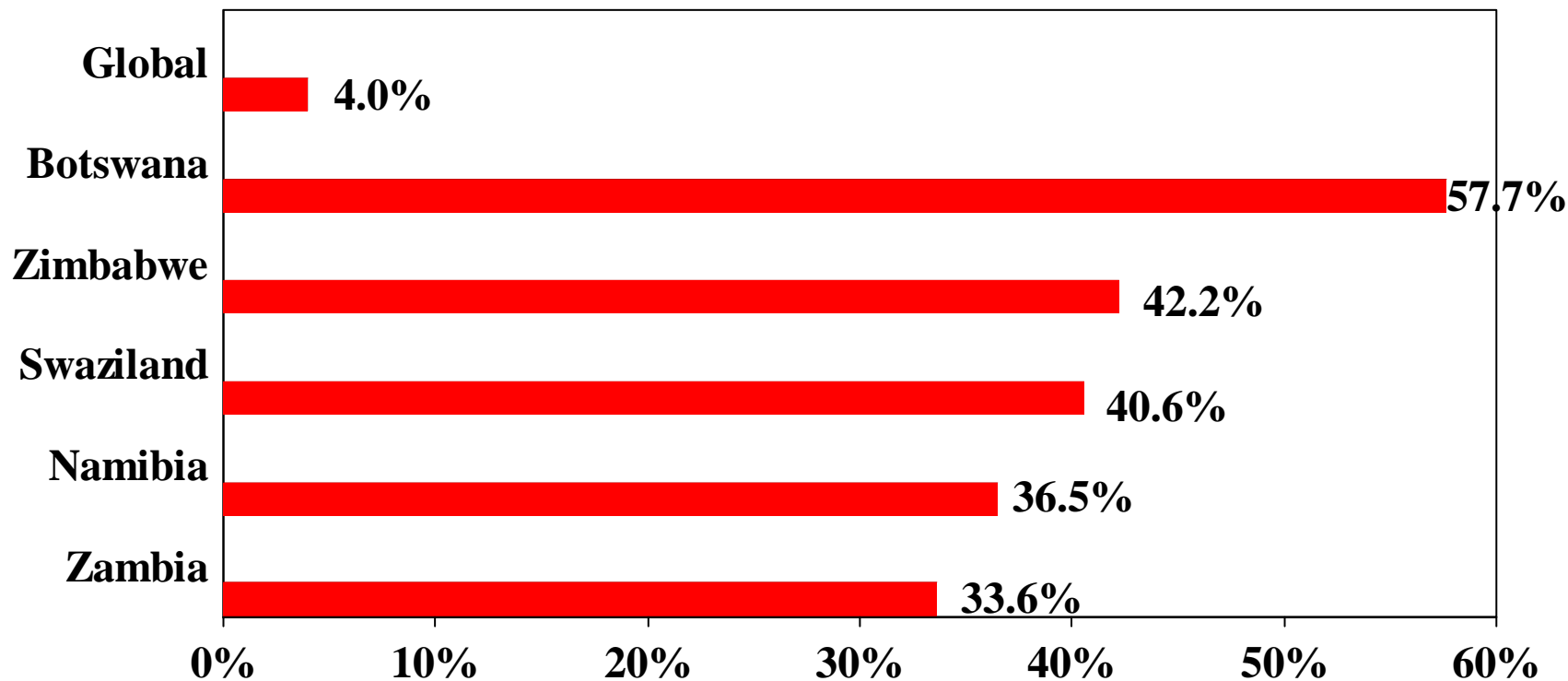




- ❑ High prevalence of infection in women of childbearing age
- ❑ Low coverage of PMTCT interventions
- ❑ Lack of male partner involvement
- ❑ Multiple concurrent partners
- ❑ Intergenerational sexual relations
- ❑ Poverty
- ❑ Stigma



Deaths Under Five Years of Age Attributable to HIV/AIDS



% mortality in < 5 attributable to HIV/AIDS



- Poorer prognosis than in developed countries for several reasons:
 - **Child survival lower in Africa in general**
 - Malnutrition and/or poverty
 - Concurrent infections (malaria, TB, diarrhea)
 - **Health systems are weaker**
 - Lack of access to health care services
 - Delayed laboratory diagnosis; PCR not available
 - Lack of access to basic HIV care and ART



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Children with HIV have faster progression of disease than adults





Category 1 (25 – 30%):

Rapid disease progression; infants die within 1 year - disease acquired in utero (during pregnancy) or during birth.

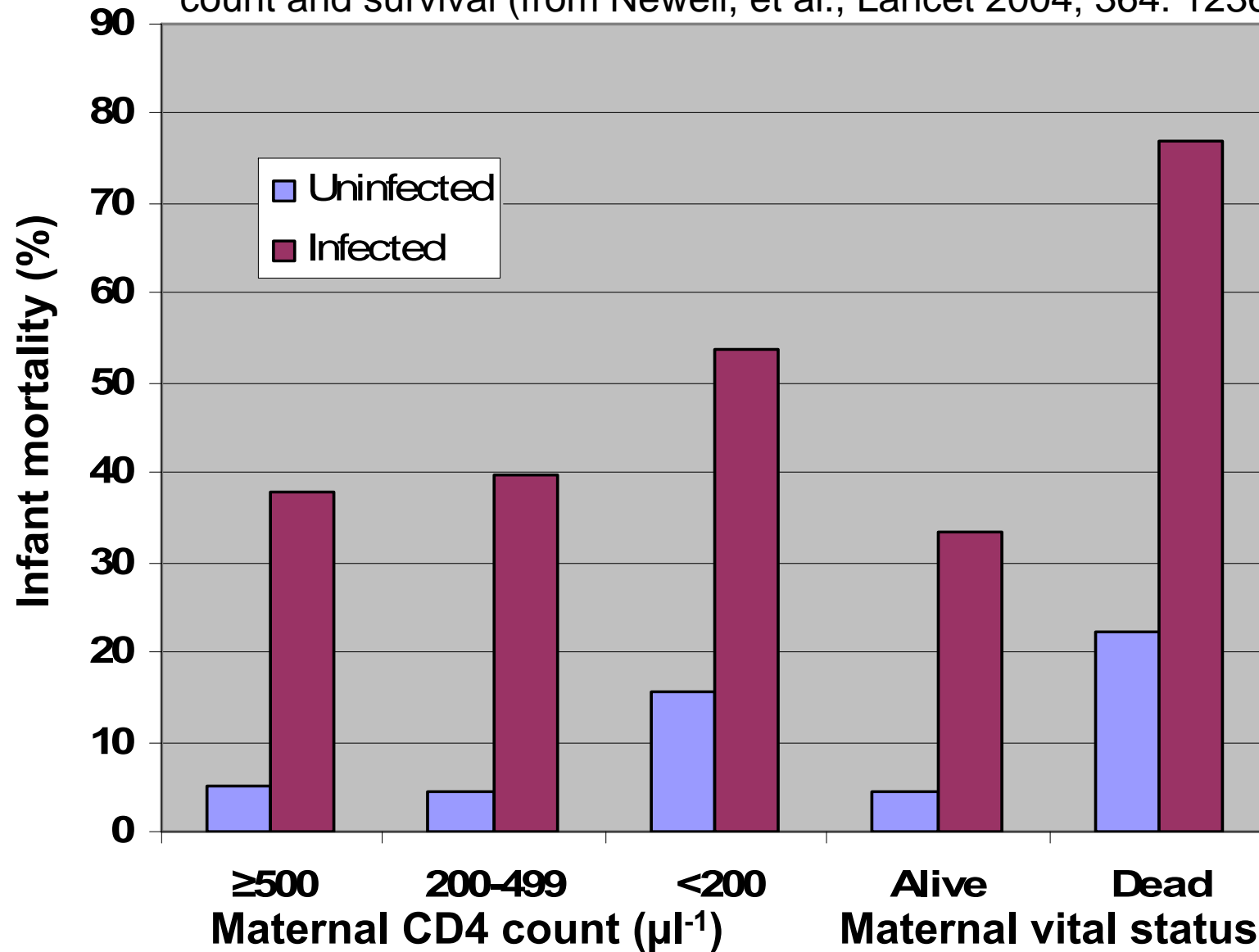
Category 2 (50 – 60%):

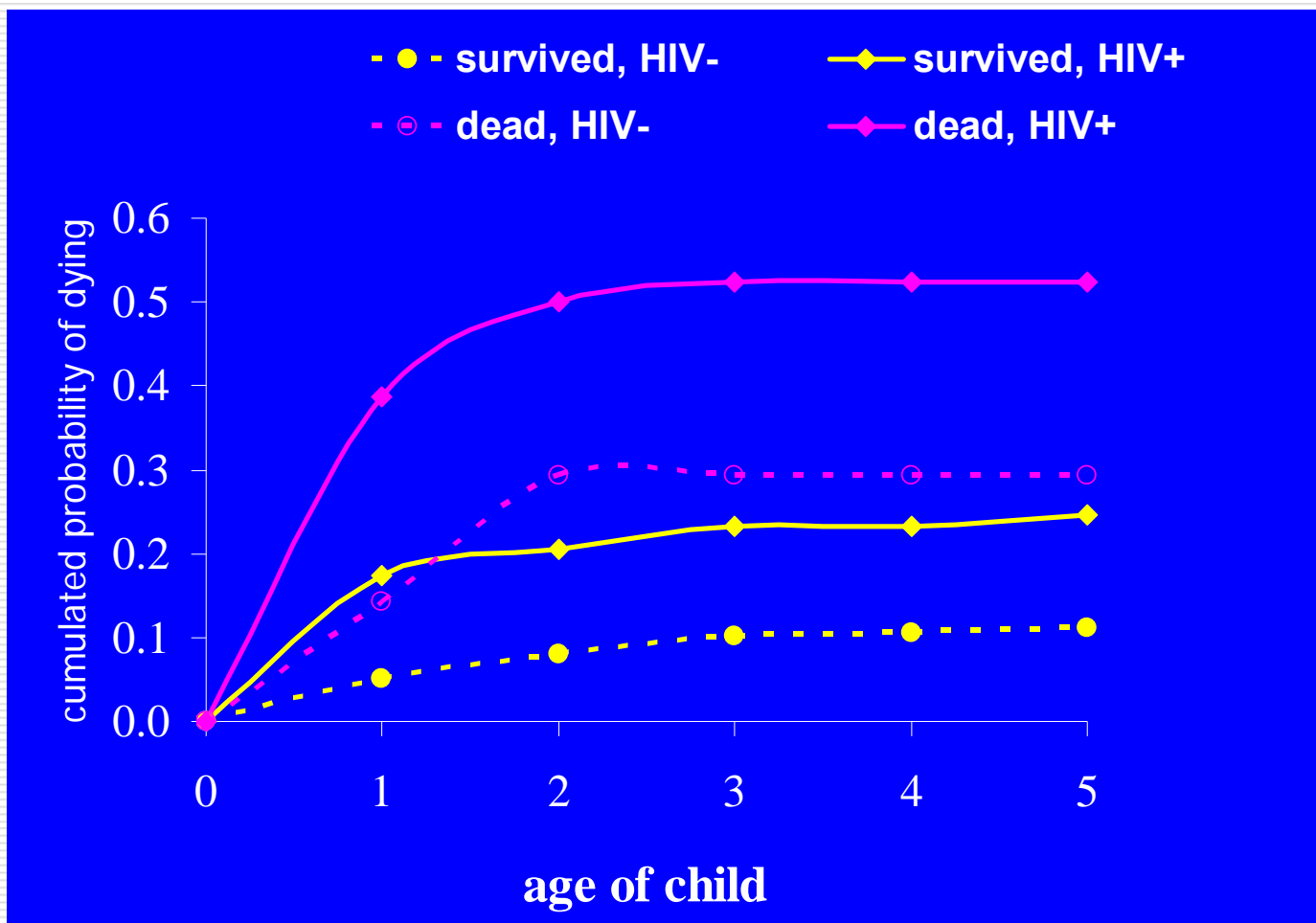
- Children who develop symptoms early in life.
- Deteriorate and die by 3 to 5 years.

Category 3 (5 – 25%):

Long-term survivors who live beyond 8 years of age.

Mortality at 15 months median follow-up among infected and uninfected infants of HIV-infected mothers in Africa according to maternal CD4 count and survival (from Newell, et al., Lancet 2004; 364: 1236)







- Maternal disease status
- Maternal viral load at delivery
- Maternal CD4 (<200)
- Rapid maternal disease progression
- Maternal death
 - Infant mortality is 2-5 x > when mother dies



- Immature immune system
- Viral load (at infection) and Infant CD4%
 - Complementary and independent factors
 - Rate of decline of CD4
 - More predictive of advanced risk of OIs >1st yr
- Infant peak viremia.
- Timing of infection
- Clinical AIDS



- Early Diagnosis is difficult
- Disease progression is faster
- Infant prognosis worse in Africa
- Health systems weaker
- Health workers lack knowledge and skills to treat children
- Pediatric formulations are less available
- Stigma
- Community sensitization



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40% of infants will die of HIV before 1 year age





- ❑ Prevention of mother to child transmission (PMTCT)
- ❑ Promotion of abstinence & delay in sexual debut for young people
- ❑ Post exposure prophylaxis (rape, sexual abuse)
- ❑ Safer sex innovations
- ❑ Safer medical/surgical practices



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Who we are

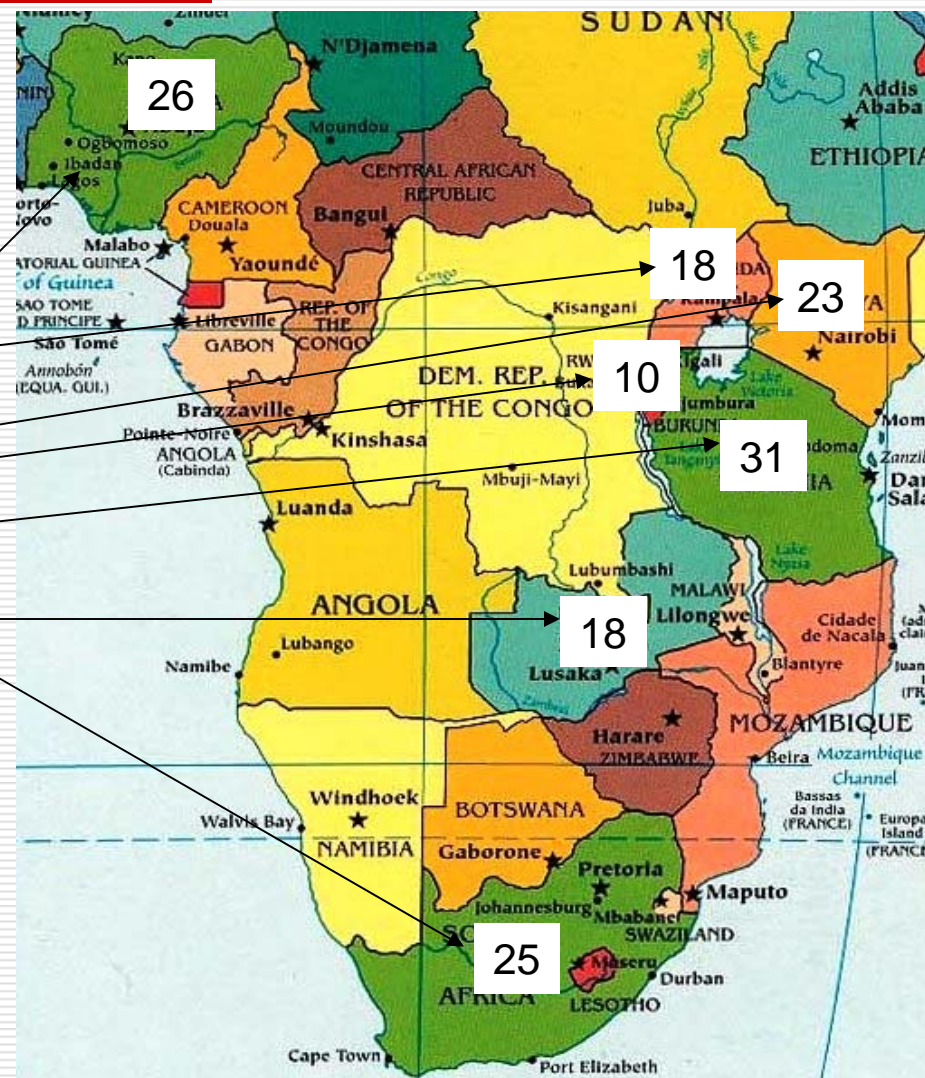
- ❑ Catholic Relief Services (CRS)
- ❑ University of Maryland School of Medicine – Institute of Human Virology (IHV)
- ❑ Constella Futures (CF)
- ❑ Catholic Medical Mission Board (CMMB)
- ❑ IMA World Health (IMA)



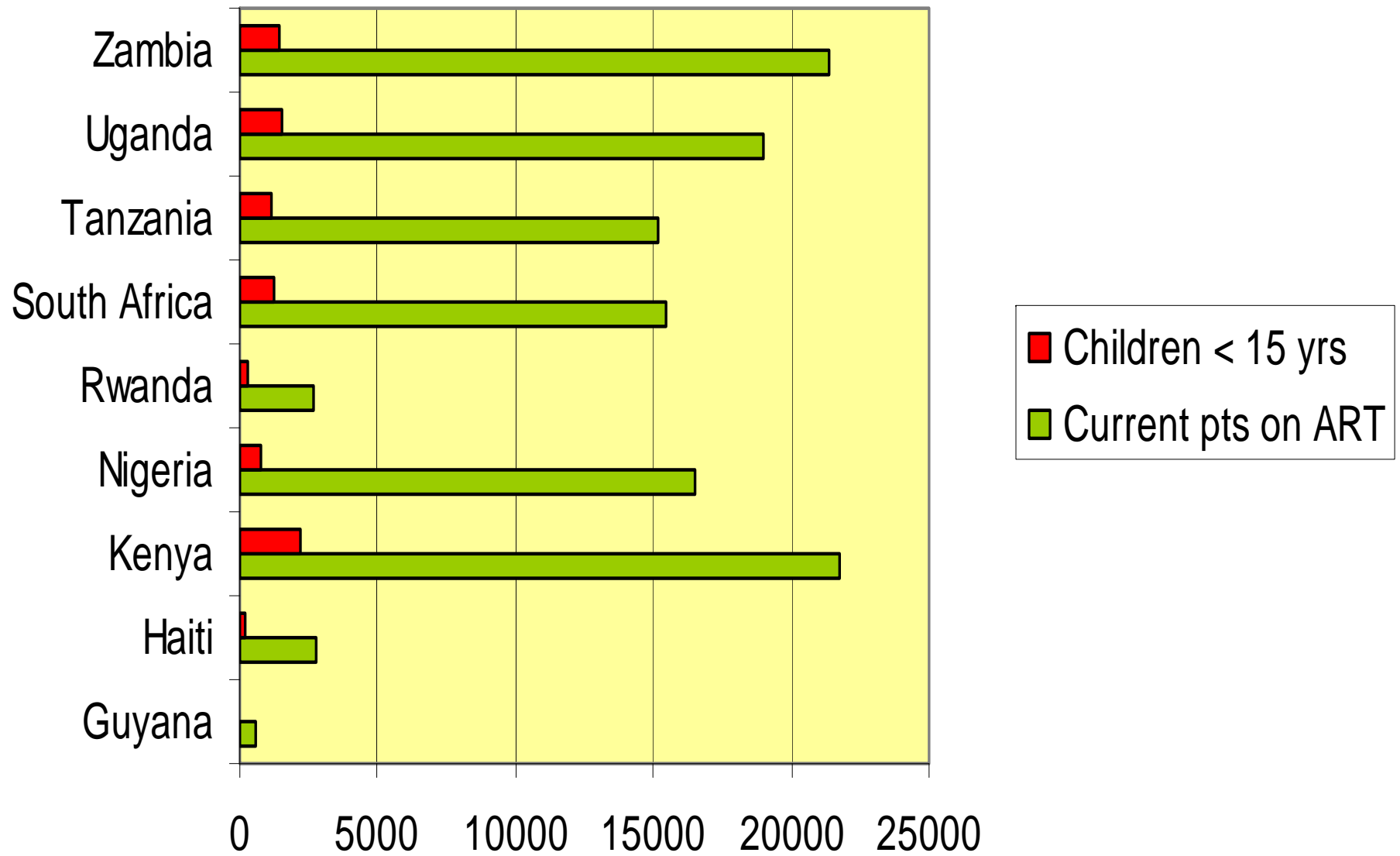
Where Do We Work?

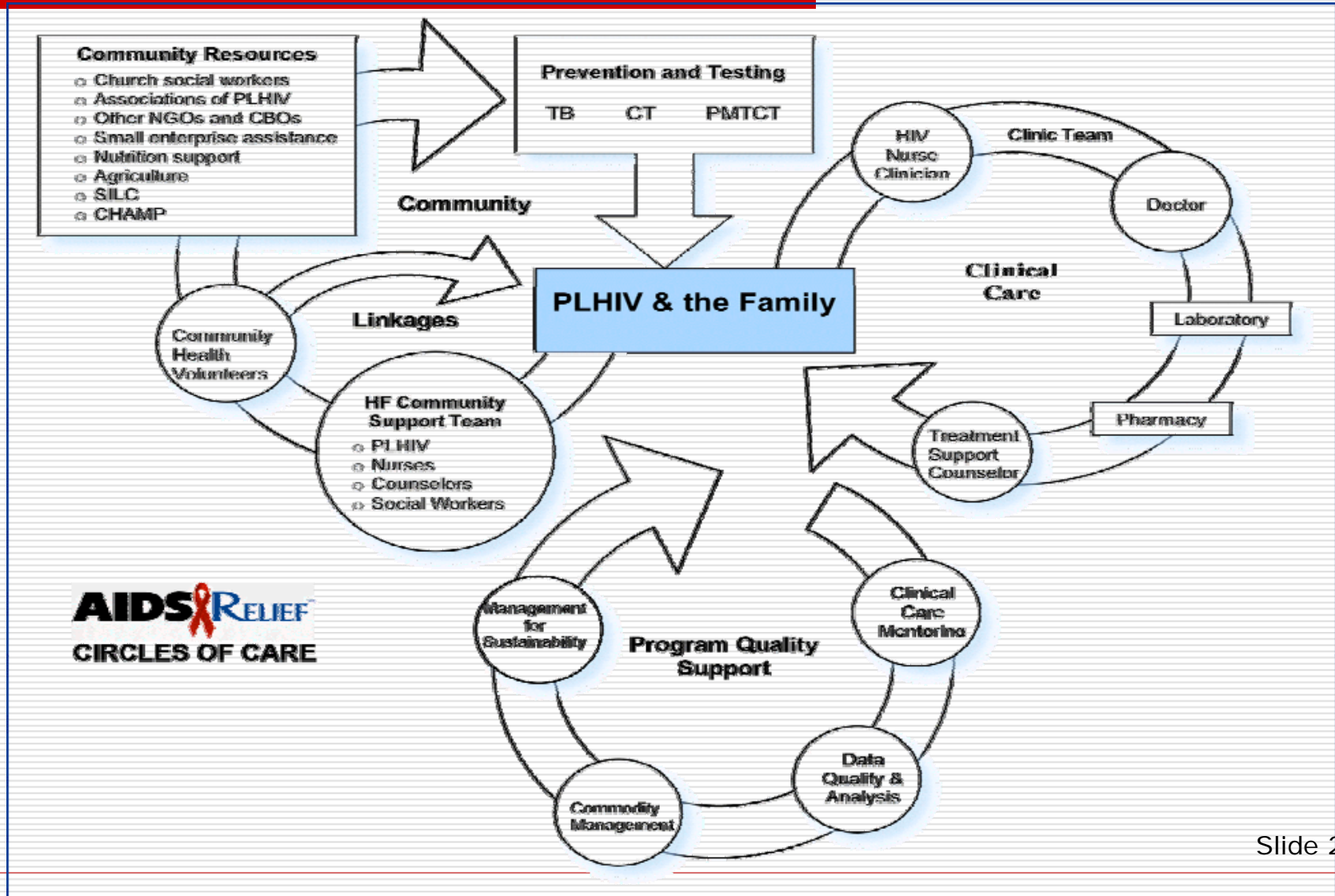


**162
Local
Partner
Treatment
Facilities
(LPTF)**



Total Patients on ART May 2008







- Test mothers who deliver without prior testing for HIV
- Pediatric wards: providing HCT to children admitted for various illnesses.
- Outpatient clinics
- MCH clinics
- TB wards (adults/children).
- Nutrition Rehabilitation Units (NRU)
- Sexually abused children/exposed to potentially infectious body fluids
- Adolescent clinics
- Community Diagnosis; OVCs programs/ orphanages, schools

Patient and family Knowledge

Access to trained health care providers

Love and
Community
support





Medical care design



Kasambya HC III

Blood samples
lab tests; CD4,
LFTs, RFTs

Villa Maria Hosp



Requisitions,
Referrals, clinical
tools for
computerization



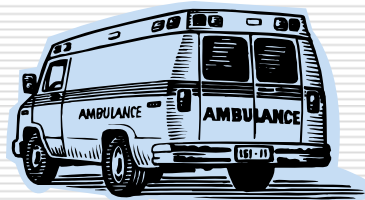
Kitanda HC III



Bigasa HC III



Kitaasa HC III NGO



Makukulu HC III NGO

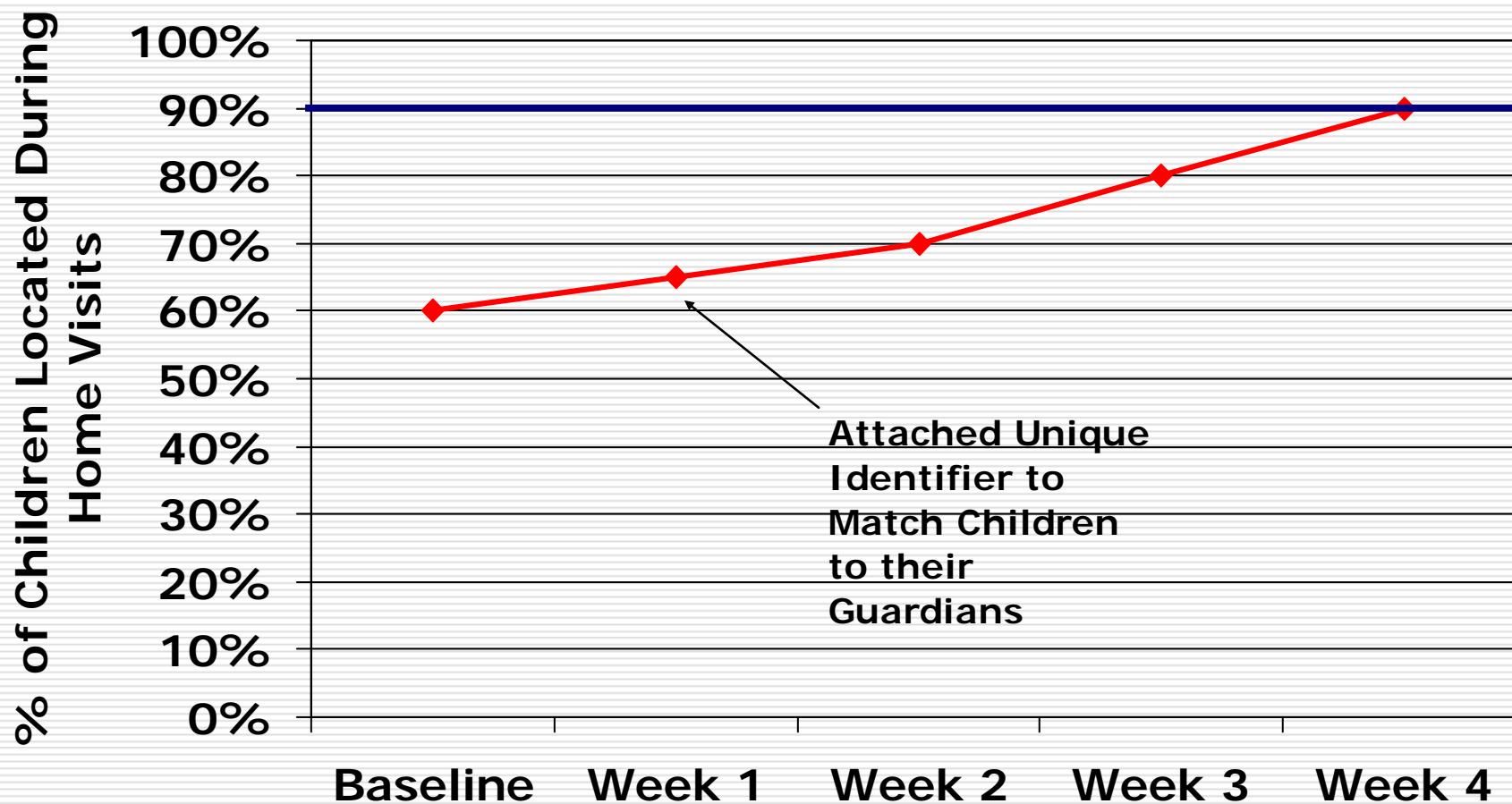


Buyoga HC III NGO

Drug supplies, support
supervision, CD4 results
back to clients, adherence
sessions at H/units, Basic
care kits



Small Test of Change Example





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**ART and Children: Is it Working?
Case studies from Nigeria**

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for the CRS OVC Forum Washington June 26, 2008





- ❑ 2-1/2 year old girl who had diarrhea, was losing weight, lethargic, and very weak. The child had never walked, and was fussy all of the time.
- ❑ Mother had tried traditional remedies and faith healers, but the child was still extremely ill
- ❑ Finally, the mother brought the child to a medical doctor since all else had failed



- The physician took a history and examined the girl, and suggested HIV testing. The mother reluctantly agreed.
- The child was found to be HIV+ and was eventually commenced on antiretroviral therapy.



- The child's appetite significantly improved, the diarrhea resolved, and so did the child's weakness.
 - In fact, the girl stopped being so fussy, and began walking for the first time in her life!
 - Two years later, no one can tell that she had been so ill!
 - The mother saw other children who were suffering like her own, and she reached out and suggested the children get tested, since she had seen the remarkable change in her own child



- 3 year old child who lives near Sokoto at the northwestern part of Nigeria
 - Travels monthly to Kano to get their meds
 - Trip takes several hours each way
 - Family has to wait at the clinic 3 hours to be seen and another 3-4 hours at the pharmacy to get their medications
 - Child initially had failure to thrive (weight loss), and had been hospitalized several times for pneumonia and diarrhea
 - Improved significantly on antiretroviral treatment



- Child came several weeks late for an appointment because they couldn't afford to get transportation to come to clinic

- Medications ran out before they were able to return



- This sets the child up for treatment failure and resistance to the medications
- Unfortunately, viral load and resistance testing is not readily available in Nigeria, so don't know if this child already has resistance
 - If the child does have resistance to one medication and we don't know about it, yet we continue the same regimen, the child will likely get resistance not only to the medications she's taking, but also to medications in the same class
 - The clinic may not even have access to medications the child needs in the event that the first line of treatment fails



- Child was referred to a newly-opened clinic much closer to where the child lived, however, the child's father was reluctant to go there since he might run into someone he knows
- Eventually, the child did go to the clinic closer to home in Sokoto



- A couple who were HIV+ chose not to have the mother go on HIV medications while she was pregnant to prevent parent to child transmission of HIV.
 - Instead, they were going to pray and rely solely on faith for the child to be HIV negative
- The child did fairly well early in life, never had major illnesses, and the child attained his developmental milestones on time.



- However, by 15 months, the child is losing weight and is no longer walking or talking. The child is tested for HIV and is HIV+.
 - Do we start therapy as soon as possible?
 - What about the family's attitude about taking medications?
 - Will they adhere to a medication regimen, or will they start meds and then stop (or worse yet, be very inconsistent) and hope that their faith will lead to the child's healing?
- Adherence counseling will be of utmost importance in determining whether the family is prepared to start medications
 - Many places don't have pediatric adherence counselors!
- Antiretrovirals work extremely well, but only when they're being taken consistently and correctly!



- ❑ 3 week old newborn brought by aunt to clinic in Bida.
- ❑ Mother has died but aunt chooses not to disclose the cause of the mother's death.
- ❑ Aunt has been trying to breastfeed this child (she has her own infant that she is breastfeeding), but this child isn't feeding vigorously.
- ❑ The child weighs 1.5 kg (3 lb 5 oz), but aunt doesn't know birth weight of the baby.



- On examination, child is extremely malnourished – has very little fat under the skin, and the skin is quite loose. Baby responds only to moderate stimulation
- Clinical team wants to admit the child, but aunt needs to:
 - Get money and belongings for the admission
 - Provide for her own infant
 - Talk with the father of the baby
 - Therefore she goes home from clinic without admission



- On follow-up with the doctors caring for the child, the child did return to be seen, and the child is improving.
- The child needs ongoing nutritional support and access to HIV testing
 - A rapid HIV test in this child will only determine if mother (or aunt, since she's breastfeeding) had HIV; we still won't know if the child is infected
 - Child needs access to early infant diagnosis testing by PCR
 - PCR is the gold standard to diagnose infants less than 18 months of age



- Antiretroviral medications not only can SAVE lives, it can – in some instances – reverse a child’s developmental delay or regression
- However, there are many, many challenges that patients, families, and health care teams/facilities face in providing HIV care and treatment
 - Stigma, transportation, poverty, malnutrition, training and retention of health care workers, adequate laboratory facilities, consistent supply and availability of medications, drug interactions, cultural and religious beliefs, adherence to complex treatment regimens, refrigeration/storage of medications (by families and facilities), disclosure of HIV status (to others and to the child)...just to name a few!



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with ANECCA

**PSYCHOSOCIAL CARE & COUNSELING
FOR HIV INFECTED CHILDREN AND
ADOLESCENTS
A Training Curriculum**



- ❑ Children are **unique**... they are not small adults
- ❑ They have physical, psychosocial and spiritual needs that are **different** and our responses need to be different than those we would give to adults.
- ❑ Effective care requires us to understand these differences...



- ❑ Ability to communicate in an age appropriate way
- ❑ Ways to communicate with children – play, drawing, story telling, child friendly environments
- ❑ Basic primary health care should not be forgotten – immunizations, growth monitoring, nutrition.
- ❑ Critical issues: counseling, disclosure



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A child's right to be seen and
be heard

- UN Convention on the Rights of the Child- 1989 states in Article 17 that “children have a right to information being presented in a such a way to take account of their linguistic and communication needs”



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Good ground rules for
effective Communication

Listen with your
EYES

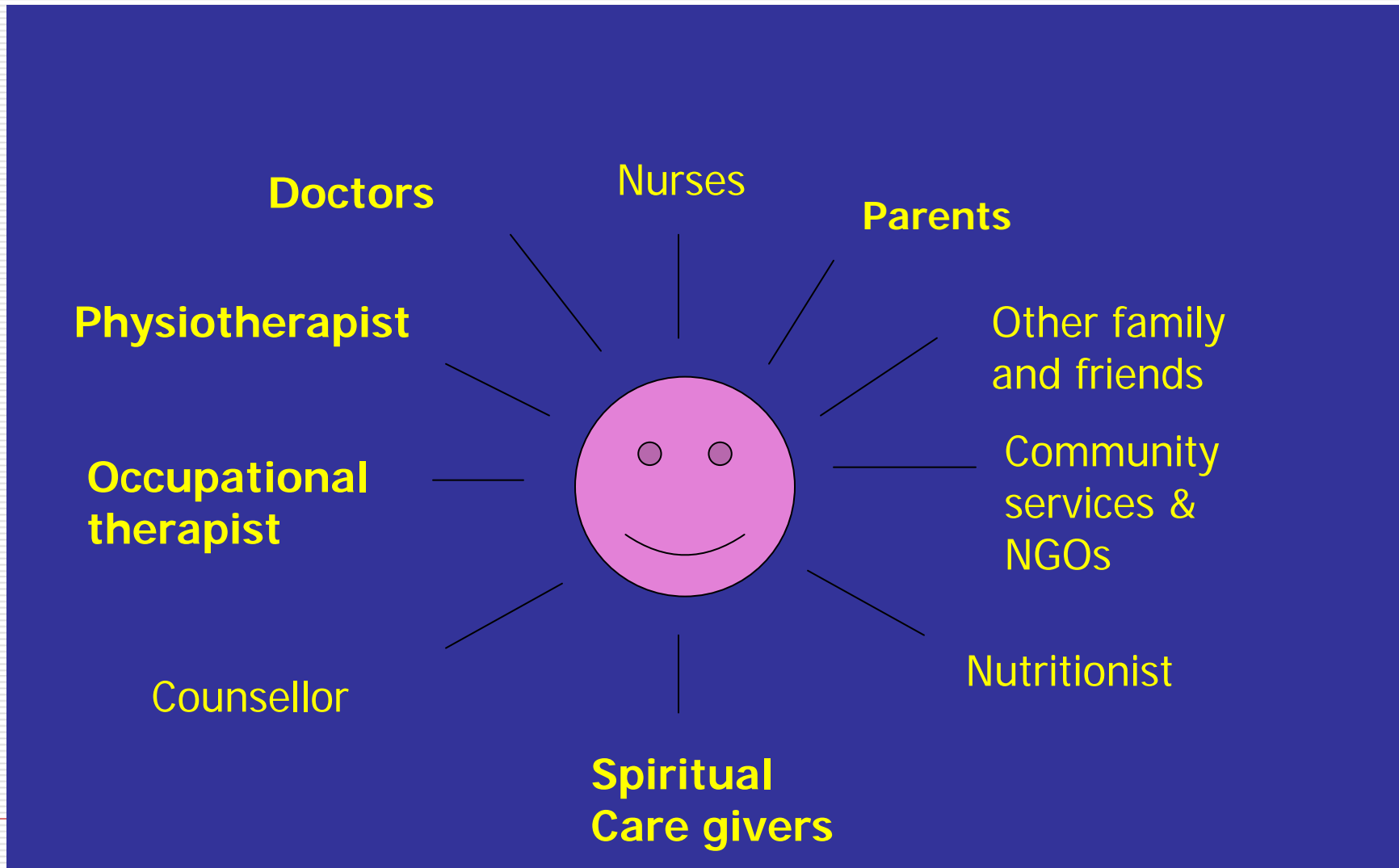


EARS



HEART







- Pediatric Counseling curriculum:
 - African based course for increasing skills in pediatric HIV care and treatment health workers
 - Comprises 14 modules
 - Participatory
 - Materials consists of:
 - Set of Powerpoint slides
 - Facilitation Manual
 - Film of unscripted interviews with children with HIV
 - Job aides
 - Handbook (to be completed)



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Video clip Brian and Alijah



- ❑ Understand and address individual needs within a family.
- ❑ Assess family characteristics and roles, functions, strengths and weaknesses
- ❑ Be ready to discuss various problems that affect the family
- ❑ Enhance family interactions
- ❑ Advocate on the behalf of the family
- ❑ Provide preventive, supportive and therapeutic interventions



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- Key to addressing paediatric HIV infection is prevention
 - Strengthen effective PMTCT programs

- Link with HIV treatment sites to get Mums and their families into care



10 pillars of comprehensive care in HIV infected children:

1. Confirmation of HIV diagnosis
2. Staging of Disease
3. Treatment of acute infections and other OI's
4. Immunization
5. Regular monitoring of growth and development
6. Nutritional care, supplementation and advice



7. Prevention of infections e.g. PCP (cotrimoxazole), Malaria, Diarrhoea
8. Counselling for and providing ART.
9. Providing care, treatment and psychosocial support for mother and family
10. Planning for/providing follow up including community support



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Video clip - Makdot



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Thank You



Slide 52



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