CCABA satellite

How community-based organizations can help to end vertical transmissions

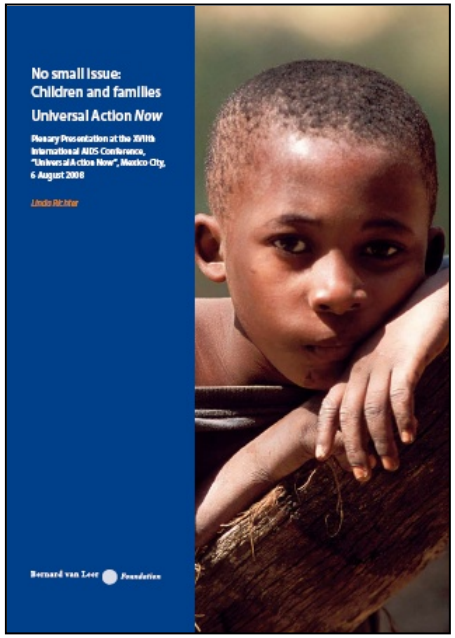
Linda Richter

16th ICASA Conference *Own, Scale-up and Sustain*

5 December 2011, Addis Ababa

CCABA's mission .. children

- IAS Bangkok 2004
- Toronto 2006
  - Families, scale, integration
- JLICA & Mexico plenary 2008
  - Poverty, social protection
- Vienna 2010 - Family-centred services
- Washington 2012 – PMTCT-community



Why this Road to Washington… ?

- Global focus on PMTCT
- Potential to muster "OVC community" capacity to improve child and family health and wellbeing through:
  - Community action
  - Family-centred approaches
  - Social protection

GLOBAL COMMITMENTS TO PMTCT

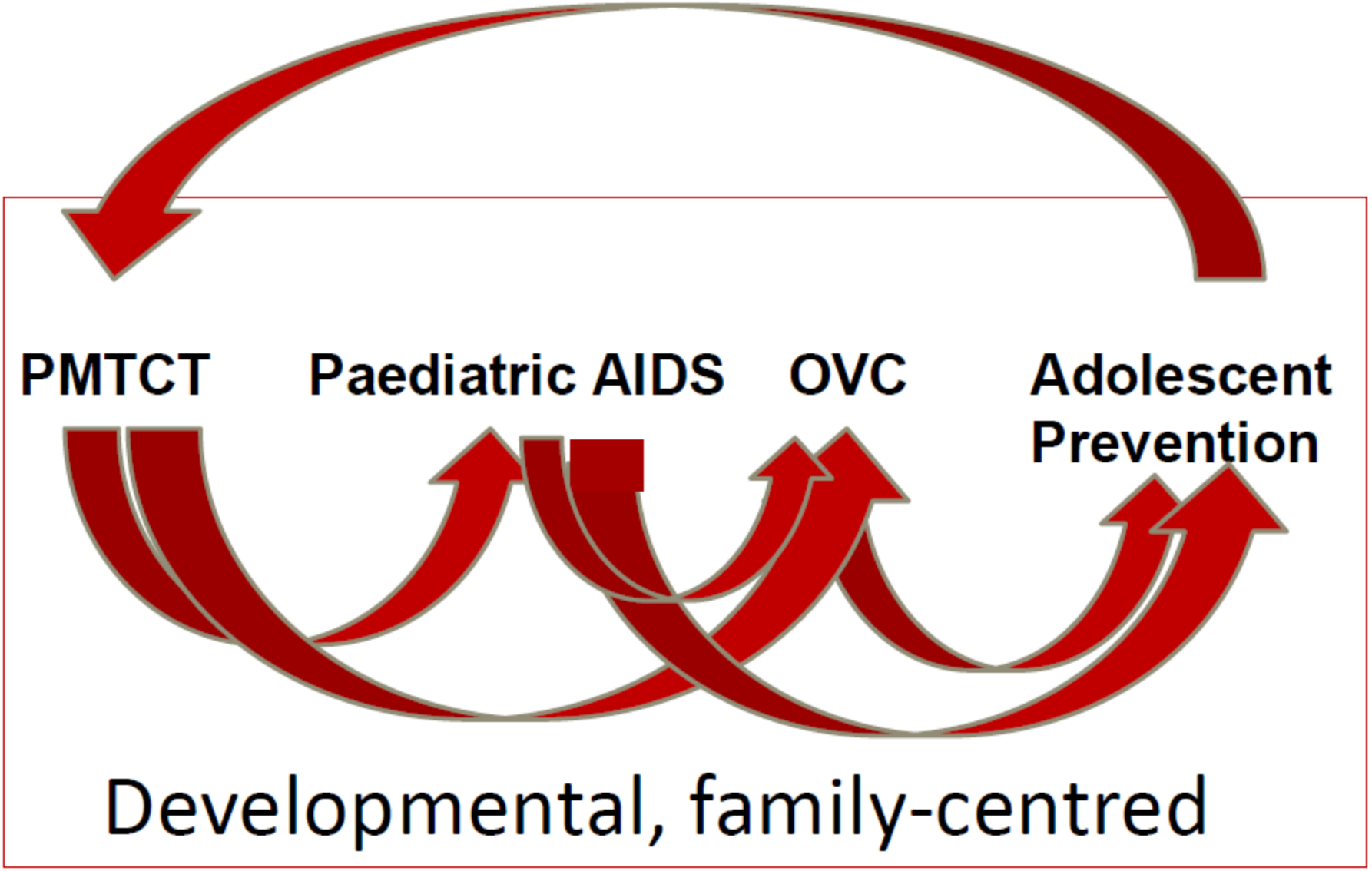
Most significant and substantial commitment to children and families since the start of the epidemic

… alive with opportunities …

Vision: 4 prongs and more

- Primary prevention of HIV infection among sexually active young people
- Prevention of unwanted pregnancies
- Prevention of vertical infection
- Ongoing care for women, children and their families

Integrated, family-centred care across the lifecycle

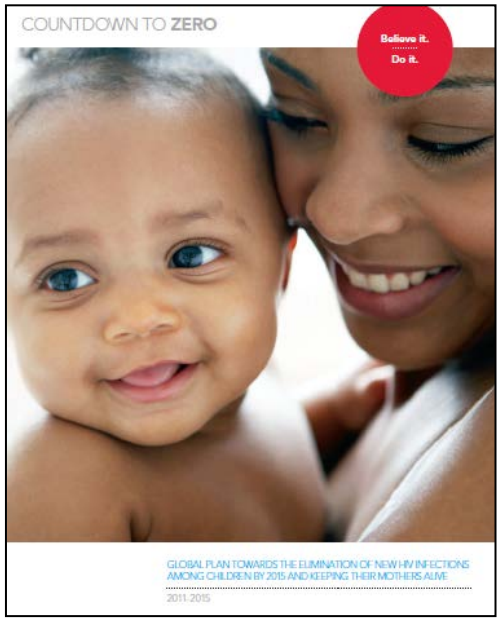

PMTCT
Paediatric AIDS
OVC
Adolescent Prevention
Developmental, family-centred approaches

Global targets

Overall Targets

1. REDUCE THE NUMBER OF NEW HIV INFECTIONS AMONG CHILDREN BY 90%.

2. REDUCE THE NUMBER OF AIDS-RELATED MATERNAL DEATHS BY 50%.



Aspirational target – 90%

To move from current performance to a reduction of 90% in 25 highest burden countries (Mahy et al, 2010):

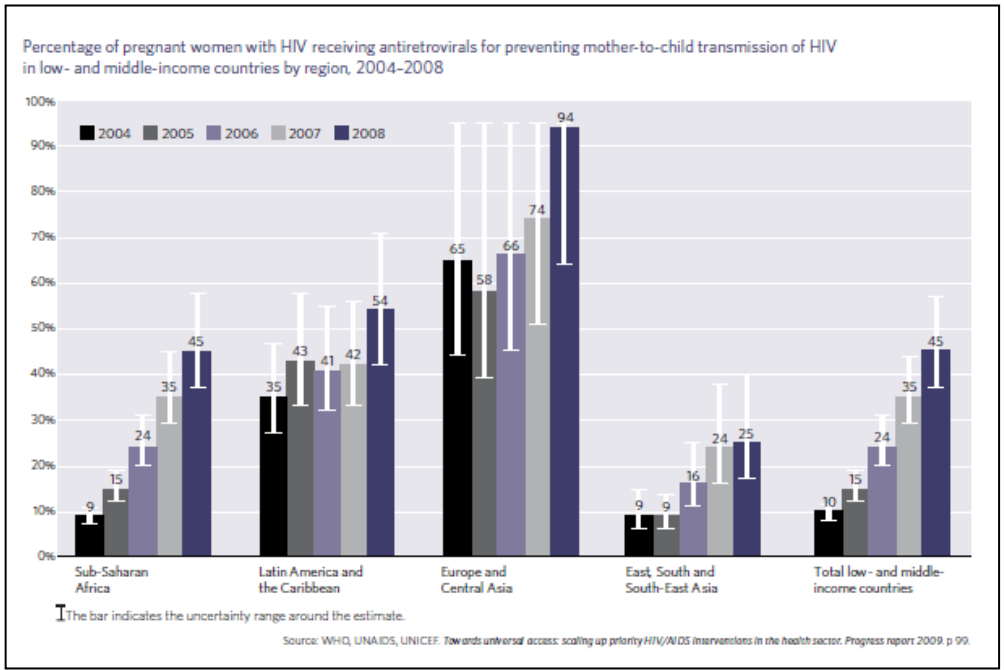
60% - will have to reach 90% of women with WHO ART/ARV regime

73% - as above
+ primary prevention →50% reduction
+ 0% unmet need by FB by HIV+ women

79% - as above
+ limit breastfeeing to 12mo

Tough ask, given …

- Only 26% of pregnant women in LMICs received an HIV test in 2009 (21% in 2008)
- Only 53% HIV+ received ARV drugs to reduce vertical transmission; 30% NVP
- 51% HIV+ women assessed for own eligibility for ARV
- 15% of babies tested before 2 months
- 14% babies on cotrimoxazole (8% in 2008)

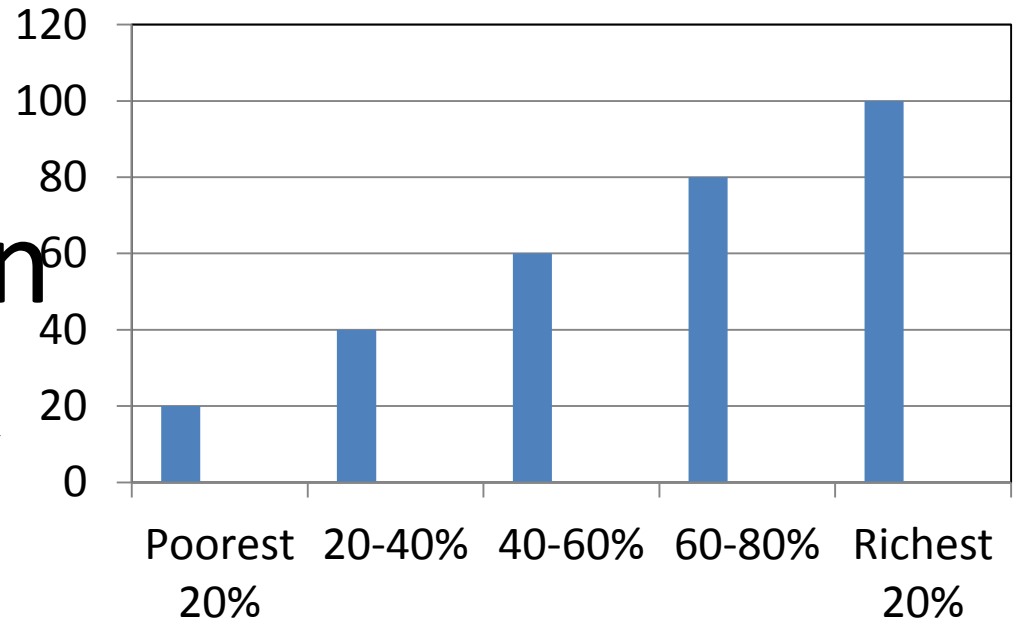


Inequities

- Marginalized groups
  - Eg sex workers, drug users

- Poor women

  - illustrative



What role for community?

- Help achieve aspirational targets - implementation challenges
- Challenge inequity, assist with redress
- Hold leaders accountable to their vision and for their actions eg targets – HIV-free survival at what age (6wks, 5y)?

What can "community" do

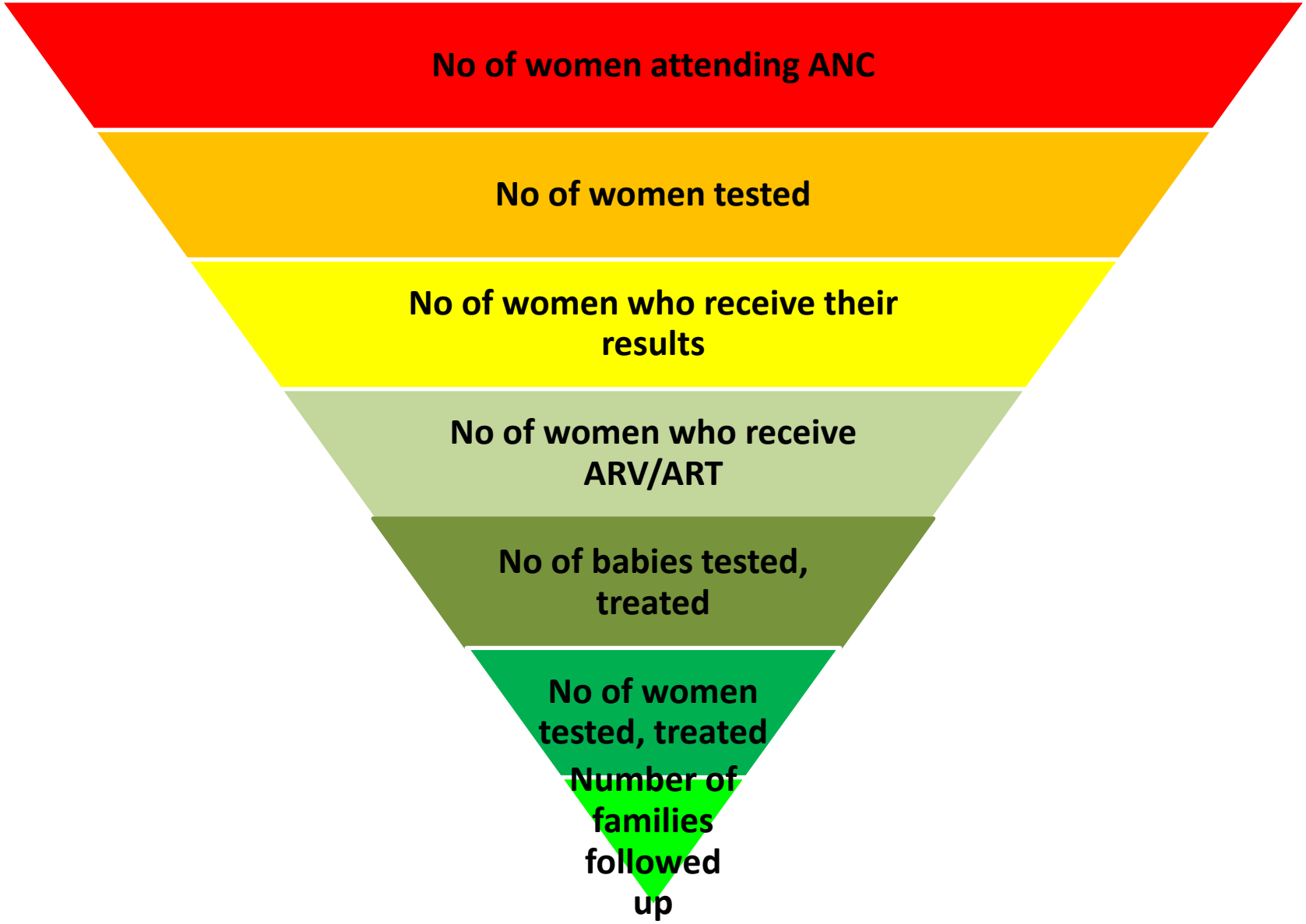
- Advocate / demand:
  - Comprehensive, equitable quality services
  - Test and expand promising practices
- Improve community knowledge & norms
- Help marginalized groups access services
- Support women and families
- Promote child health and development

Implementation challenges

Too many:

- women not reached
- women and children not followed up and treated
- male partners and children not tested
- families without support
- opportunities missed

Too many women, children and families lost



Cascade, not a funnel

Everyone gets services as required, each step of the way

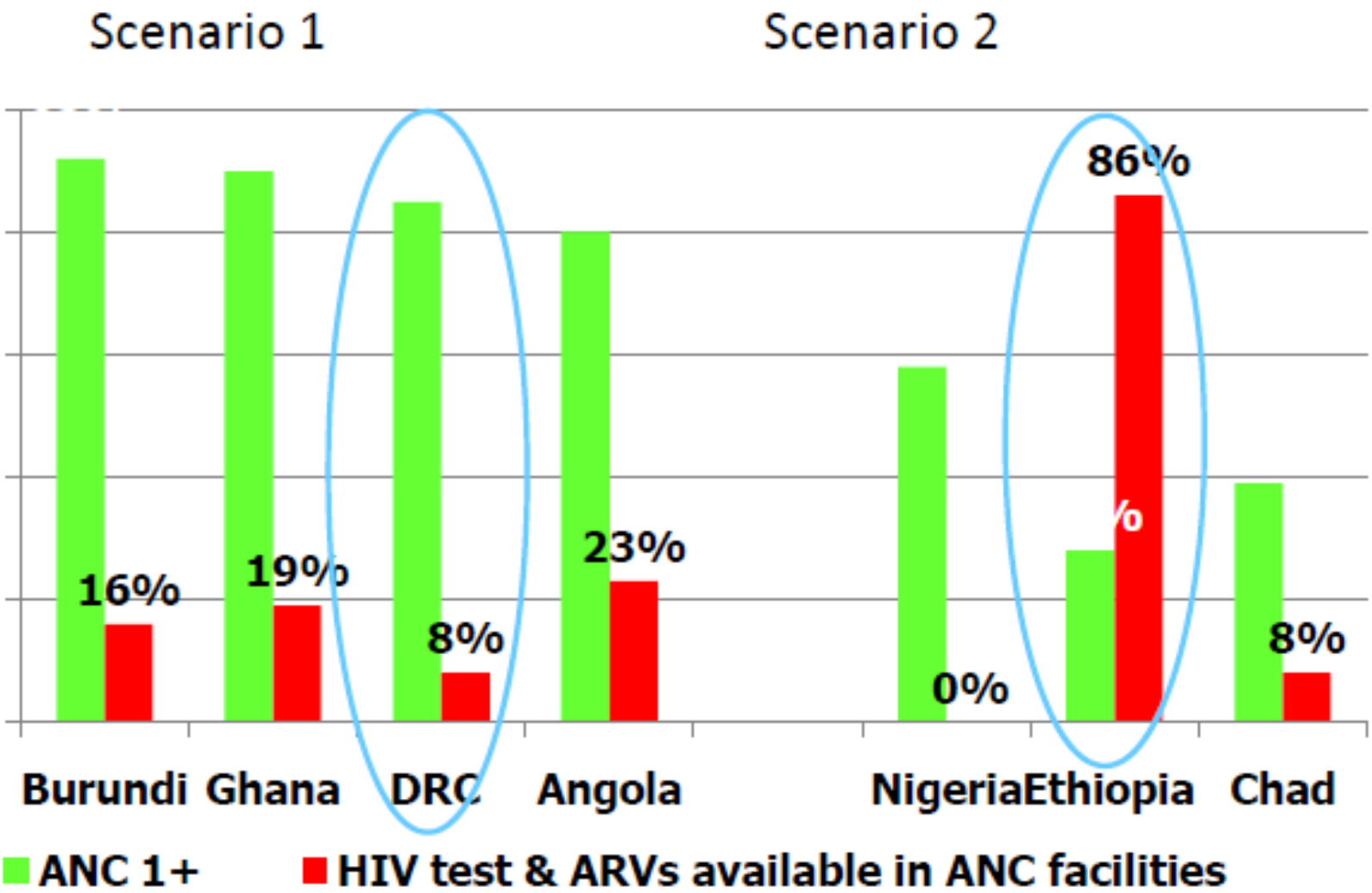
Reducing transmission requires high levels of participation every step of the way

Enrolment & retention

100 women

Scenario 1		Scenario 2	
Enrol (92%)	92	Enrol (95%)	95
Test (75%)	68	Test (95%)	90
ARV (50%	34	ARV (95%)	86
Transmission	2.2%	Transmission	2.2%
But didn't reach	66	But didn't reach	14
Transmission	25%	Transmission	25%
Population 6w	17.2%	Population 6w	5.4%

Coverage and health-seeking behavior



ource: DHS, MICS and MIS, 2004-2008; UNAIDS and UNICEF, Towards universal access: scaling up priority HIV/AIDS terventions in the health sector: progress report, 2010. Slide courtesy of Chewe Luo.

Promising practices

- Couples, home-based testing (disclosure, links to treatment, id children)
- Fertility choices for HIV+ couples
- Routine 6-week testing of all infants (improve prevention, treatment)
- Involvement of men (PMTCT, child health & development)
- Family-centred approaches
- Companionship

Community knowledge/norms

- Improve knowledge:
  - Make policy & program changes accessible through media and other channels (eg early antenatal care, breastfeeding)
- Influence norms through social mobilization
- Support early adopters

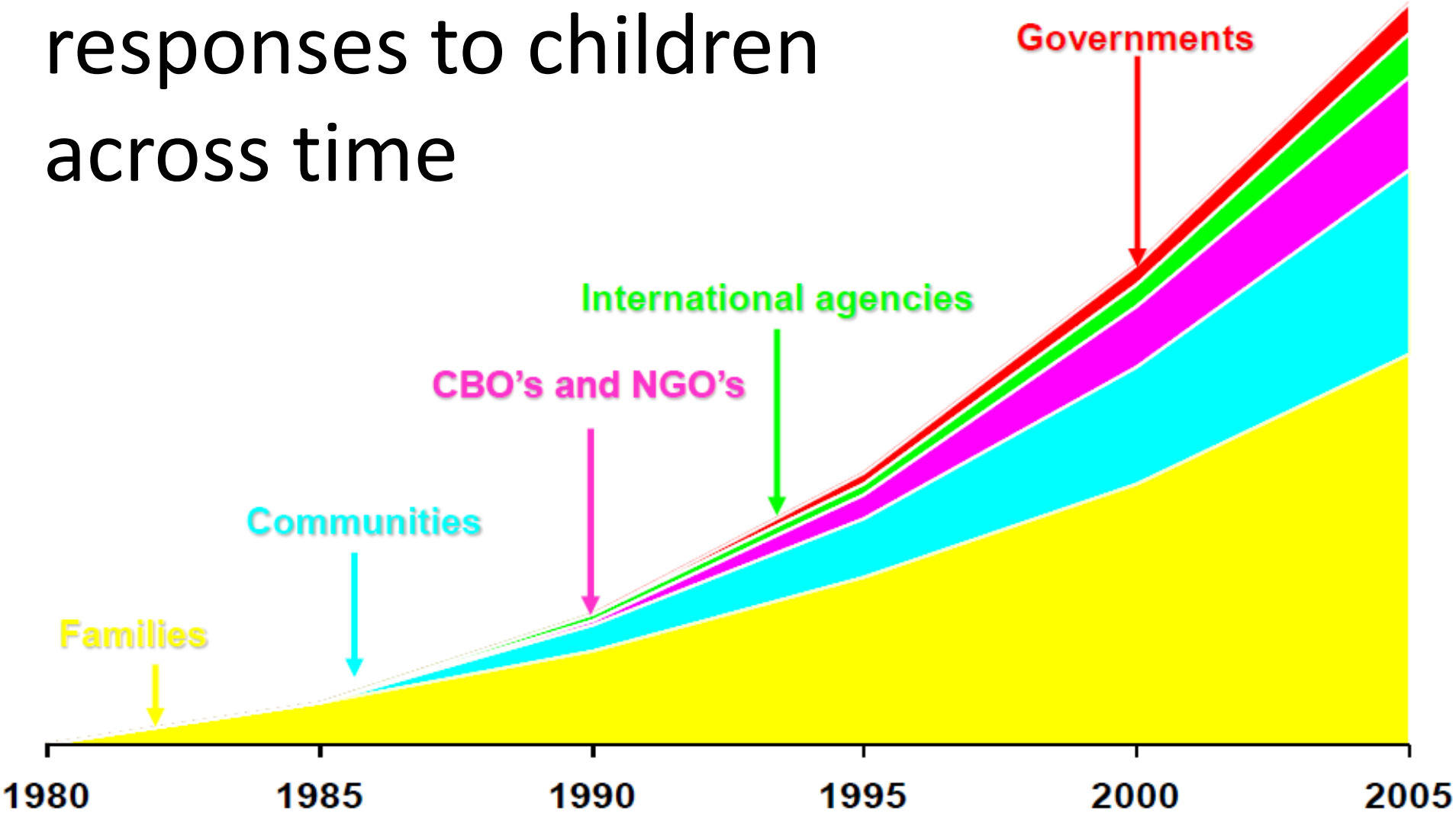
Support women & families

- Economic support
  - Cash transfers, treatment subsidies
  - Incentives to overcome opportunity costs – food packs etc
- Health support
  - Mentors, buddies, CHWs
- Social support
  - Companionship groups, home visits

“OVC” community can help

- Massive “workforce”, committed to the wellbeing of children
- Many trained and organized
- Extensive networks with deep penetration in communities
- Experienced in working holistically and with families on behalf of children

Development of responses to children across time



Notional illustration – Forster (2006)

Role not yet recognized

- “Sidelined, siloed and silent”
- Cut-off from:
  - prevention (young people, PMTCT)
  - treatment (adults and children)
  - care and support for families and
  - palliative care
- Potential role in epidemic not realized, recognized or resourced

PMTCT also cut off

- Life skills and sexuality education
- Primary HIV prevention
- Reproductive & other health services
- Integrated Management of Childhood Illnesses
- AIDS treatment and support
- Community-based “OVC” support

Time to step up …

The Investment Framework

Health Policy

Towards an improved investment approach for an effective response to HIV/AIDS

*Bernhard Schwartländer, John Stover, Timothy Hallett, Rifat Atun, Carlos Avila, Eleanor Gouws, Michael Bartos, Peter D Ghys, Marjorie Opuni, David Barr, Ramzi Alsallaq, Lori Bollinger, Marcelo de Freitas, Geoffrey Garnett, Charles Holmes, Ken Legins, Yogan Pillay, Anderson Eduardo Stanciole, Craig McClure, Gottfried Hirnschall, Marie Laga, Nancy Padian, on behalf of the Investment Framework Study Group**

Substantial changes are needed to achieve a more targeted and strategic approach to investment in the response to the HIV/AIDS epidemic that will yield long-term dividends. Until now, advocacy for resources has been done on the basis of a commodity approach that encouraged scaling up of numerous strategies in parallel, irrespective of their relative effects. We propose a strategic investment framework that is intended to support better management of national and international HIV/AIDS responses than exists with the present system. Our framework incorporates major efficiency gains through community mobilisation, synergies between programme elements, and benefits of the extension of antiretroviral therapy for prevention of HIV transmission. It proposes three categories of investment, consisting of six basic programmatic activities, interventions that create an enabling environment to achieve maximum effectiveness, and programmatic efforts in other health and development sectors related to HIV/AIDS. The yearly cost of achievement of universal access to HIV prevention, treatment, care, and support by 2015 is estimated at no less than US$22 billion.

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*Members listed at end of paper

Joint United Nations Programme on HIV/AIDS (UNAIDS), Geneva, Switzerland (B Schwartländer MD, C Avila MD, E Gouws PhD, M Bartos MEd, P D Ghys MD, M Opuni PhD); **Futures**

Three categories of investment

- 6 basic programmatic activities
- Critical enablers – health system and community
- Programmatic efforts in wider health and development sectors related to AIDS.
- Rights-based approach to all services and policies

6 Basic program activities

Based on high level evidence of effectiveness

- Treatment, care and support
- Condom procurement and distribution
- Male circumcision
- Key populations programs (MSM, IDU, Sex Workers)
- Prevention of vertical transmission
- Behavior change programs

Critical enablers

Social Enablers - make possible environments conducive for sound AIDS responses:

- Outreach for HIV testing
- Treatment literacy,
- Stigma reduction,
- Advocacy to protect human rights
- Monitoring of the equity and quality of programme access and results
- Mass communication to raise awareness and support change in social norms.

Critical enablers - community

- Create demand for key interventions – participation and retention
- Communications infrastructure - information dissemination
- Help improve service integration and linkages from testing to care
- Capacity building for community-based organizational development

Community mobilization

- Community-driven **outreach and engagement** to connect people facing similar issues
- **Support** activities to enhance quality and adherence
- **Advocacy**, transparency and accountability efforts at country and local levels to ensure that high-quality health services are available and accessible to vulnerable populations.

Synergies - development sectors

- Health systems and multiple health issues
- Gender equality efforts
- Education and justice sectors
- Social protection and welfare
- Food security
- Community systems

Good ways to hold hands

Health services and systems

Community action (especially "OVC" groups)

Wellbeing of children and families

HEALTHY PARENTS, HEALTHY CHILDREN, HEALTHY FAMILIES.

**YOUR HEALTH, YOUR PARTNER'S HEALTH,
YOUR CHILDREN'S HEALTH:
WE KNOW HOW IMPORTANT THEY ARE TO YOU —
AND WE WANT TO HELP**

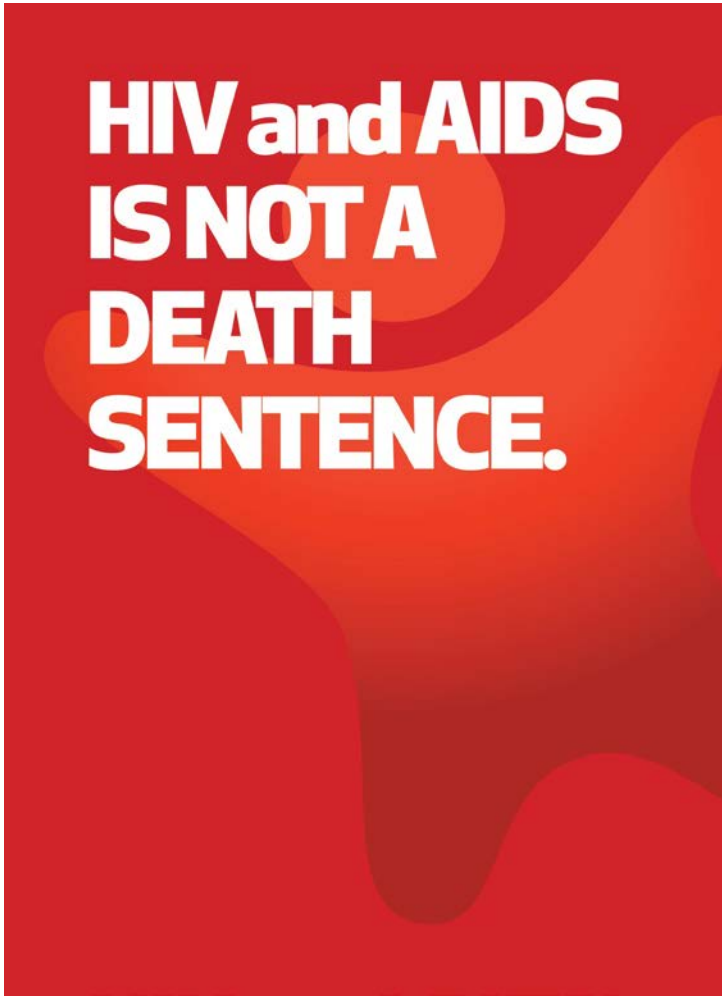
**HIV and AIDS IS NOT A DEATH SENTENCE.
HIV and AIDS CAN BE PREVENTED.
HIV and AIDS CAN BE TREATED OR CONTROLLED**

Purpose

- Couldn’t find simple materials
- Enable the 100’s partners of CCABA members to play a role in PPTCT expansion and quality
- With simple information
- Flexible commitment
- Focusing on key issues

Key issues

- Hope and encouragement
- Support and
- Partner testing
- Disclosure
- Norms and stigma
- Adherence
- Infant feeding
- Health promotion



Strengths of CBOs

- Community endorsement
- Contact and reach
- Trust, holistic
- Family-centred
- Home visiting
- Networked

Roles

- Information and support
- Companionship
- Accompaniment
- Help with disclosure
- Retention in treatment
- Family planning

THIS IS THE BACK PAGE OF THE BROCHURE.

PUT YOUR ORGANIZATION'S INFORMATION HERE AND DELETE THIS TEXT.

Put information about your organization, where to find you, what you do, etc.

This pamphlet was produced with guidance from the Coalition for Children Affected by AIDS and its members, in solidarity with several international campaigns -- by UNAIDS, UNICEF, WHO, The Global Fund, PEPFAR and others. Its purpose is to support families and communities a) to prevent women and men from becoming infected with HIV, b) to help women prevent or avoid unwanted pregnancies, c) to keep parents alive through treatment, d) to treat AIDS in children, and e) to support families and children so that they can enjoy a healthy life together. All of these strategies together are what are otherwise known as ‘preventing mother to child transmission (PMTCT), ‘preventing parent to child transmission (PPTCT), or ‘preventing vertical transmission’.

This pamphlet was written and designed so that it could be edited and customized by community organizations to suit local needs.

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Testing, treatment and support are getting better. Times are changing and we know more than we used to. Services are becoming more available and accessible. For instance, with proper testing, treatment, care and support:

- If you, your husband/partner or your child tests HIV-negative, you can make sure you all stay HIV-negative.
- If you test HIV-positive
  - Make sure your **partner tests** too.
  - Women living with **HIV can have a safe and healthy pregnancy and give birth to a healthy baby**.
  - You and your family can stay healthy.
  - With support, you and your family can cope with illness and difficulties that may arise.
  - You and your partner can **choose if and when you want to have another child**

Even so, we know there are still challenges. Here's how we can support you.

If you, your partner or your child tests HIV-negative, you can make sure you all stay that way.

- To be able to receive the care that you need, it's important to **get tested for HIV**. If you know your HIV status, you can **take steps to protect your baby** from contracting HIV.
- It's important to bring your **husband/partner to be tested**, and any other children you might have.
- You and your husband/partner can give each other support, especially if one of you is **HIV-positive and the other is HIV-negative.**
- It's important to go back to **get your results** because the people who tested you might not reach you to ask you to come back.
- If you or a family member tests HIV-negative, it's important to protect yourself from HIV in the future.
- Protect yourself also by getting re-tested from time to time.

- **HOW WE CAN SUPPORT YOU**
- We are happy to **support you** when you, your husband/partner or your children are tested.
- We can help you when you **tell your husband, wife or partner** your results, and support you if you are worried about how he or she might react.
- We will support you if you **fear that stigma** might affect how you are treated.
- We can **remind you to pick up your test results**, and go back with you to pick them up.
- We can help you learn about ways to protect yourself from HIV, especially if your partner or someone else in your family is HIV-positive.

Women living with HIV can have a safe and healthy pregnancy and give birth to a healthy baby who is HIV free.

- You must go to the clinic as soon as you know you're pregnant - or even before, so that you can plan a healthy pregnancy. Most medicines work better when they are started early
- Ensure that you attend clinics and **take your medicines** exactly as your health worker tells you to. You need to do this to keep yourself healthy, to protect your baby from getting HIV, and to help your baby remain healthy even if your baby is born with HIV.
- Look after yourself. Remember your **clinic appointments**.
- Be active but rest when you are tired. Eat well.

HOW WE CAN SUPPORT YOU

- We will be happy to **go to the clinic with you** the first time if you want a companion.
- We can offer support when you get tested and when you collect your results.
- We can **support you if you're worried about stigma**.
- We can help you **remember your clinic visits** and remember to take your medicine.
- We can support you, your partner or your child to **always take your medicines**, even if it gets difficult.
- If you or your family member has HIV or AIDS, or another illness, we can help explain what you should expect, and what should happen when you go to the clinic to see a health worker.
- We can work out together how you can eat healthy foods.

Women living with HIV can give birth to a healthy baby

- You must **attend all your antenatal clinics and take medicines** as directed by your health worker.
- You should go to a clinic or health centre to **give birth, or make sure there is an experienced person to help you** at home.
- At birth, you should **feed your baby the first thick milk** from your breasts. It's a special natural medicine for your baby.
- Take your **baby back to the clinic or health centre for a check-up** as soon as possible (within one month).
- For the first 4-6 months, it's important to **give your baby only breast milk** – it's the best food in the world for a baby, and your baby doesn't need anything else. The more milk the baby drinks, the more milk your breasts will make.
- It is important to take your **baby to the clinic to be tested before they are 3 months old**, and to go back for your baby's results.
- Make sure to take your **baby for immunizations** and give your baby medicine exactly as the clinic or health centre tells you. It's important to make sure that your baby gets medicine to treat illness and to prevent infections. Ask your health worker for advice when you visit the clinic or health centre.
- As much as possible, **share instructions for baby medicine** with your husband/partner and your family, so that they also understand what needs to be done to keep your baby healthy.
- **Look after yourself**. Be active but rest when you are tired, and eat well.

HOW WE CAN SUPPORT YOU WITH YOUR BABY

- We can help you to remember to take your baby to the clinic and to **give your baby medicine** exactly as the clinic told you.
- We can help you to **keep breastfeeding** your baby.
- We can help you explain feeding and the baby's medicine to your family.
- We can tell you about healthy foods to regain your strength after birth.

You and your family can stay healthy, and you can cope with illness and difficulties that may arise

- Ensure that you **take your medicines** exactly as the clinic or health centre told you.
- It's important to **tell the heath worker if you feel unwell**. They will test to see if you need new medicine.
- It's important **to ask for help** when you need it. The earlier you get help, the better it will work.
- When people in your family feel sick, they also need to go to the clinic or health centre. They can stay well if they get tested early for HIV and take treatment.
- Your **family can support each other** to all stay well.
- **Look after yourself**. Be active but rest when you are tired, and eat well.

HOW WE CAN SUPPORT YOU

- We can help you to **remember to take your medicine** exactly as the health worker told you.
- We will be happy to **visit you at home** if you feel lonely, worried or sad, or need our help.
- We can **introduce you to other women** who are going through the same things as you.
- We can try and help you if you have problems at home or with your baby.
- We can **introduce parents and family members to other families** who are going through the same things.
- We can support you **if health workers at the clinic or health centre stigmatize you** or discriminate against you or your family.
- We can **accompany you to the clinic** if you need support.

You and your husband/ partner can choose when or if you want to have another child

- **Spacing babies out**, with a few years between children, is better for you and your children's health. You and your husband/partner should talk about family planning so that your babies don't come too close together. Ask the clinic or health centre for help.
- If you don't want any more children, it's important to **know how not to get pregnant.**
- People might make judgments about whether you can or should have a baby, either because you are HIV positive or because of who you are or what you do. But **the choice is yours**, and you have a right to health services if you decide to have a baby, no matter who you are or what you do.

HOW WE CAN SUPPORT YOU

- We can **talk to you about family planning**.
- We can **accompany you to the clinic** or health centre if you are uncomfortable talking to a health worker about family planning.
- We can **support you if you're feeling stigmatized** about your choices to have a baby or not to have a baby.