“The Road to Washington”

Mobilizing communities to create a supportive environment to help eliminate vertical transmission

SETTING THE SCENE

Building on Success: Understanding how community responses can contribute to successfully scaling up effective PMTCT programming

Linda Richter
2-3 December, 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 ... ?

- CCABA’s mission ... children
- Global focus PMTCT – commitment, opportunity for children, families
- Avert narrowing of goals
- Potential of “OVC community” capacity
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
Developmental, family-centred approaches

PMTCT  Paediatric AIDS  OVC  Adolescent Prevention
GLOBAL COMMITMENTS TO PMTCT

Most significant and substantial commitment to children and families since the start of the epidemic
Alive with opportunities ...
Global Plan

**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%**.

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**Prong 1 Target**
Reduce HIV incidence in women 15-49 (and 15-24) by 50%.

**Prong 2 Target**
Reduce unmet need for family planning among women living with HIV to zero (MDG goal).

**Prong 3 Target**
Reduce mother-to-child transmission of HIV to 5%.

- 90% of mothers receive perinatal antiretroviral therapy or prophylaxis.
- 90% of breastfeeding infant-mother pairs receive antiretroviral therapy or prophylaxis.

**Prong 4 Target**
Provide 90% of pregnant women in need of antiretroviral therapy for their own health with life-long antiretroviral therapy.
Targets: UNAIDS

Target 3.
Eliminate mother-to-child transmission of HIV by 2015 and substantially reduce AIDS-related maternal deaths

Indicators
3.1 Percentage of HIV-positive pregnant women who receive antiretrovirals to reduce the risk of mother-to-child transmission
3.2 Percentage of infants born to HIV-positive women receiving a virological test for HIV within 2 months of birth
3.3 Mother-to-child transmission of HIV (modelled)

TARGETS AND INDICATORS

Progress towards the targets in the UN General Assembly 2011 Political Declaration on HIV/AIDS will be monitored using the following indicators. Some indicators may track multiple targets.
Aspirational targets

Achieving elimination: Modelling number of new HIV child infections:
- PMTCT coverage/regimen at 2009 levels
- Prong 3 (ARV/ART to 90% of HIV+ pregnant women)
- Prongs 1, 2 and 3 (Incidence, FP and ARV/ART)
- Prongs 1, 2, and 3 and limit BF to 12 m

Different scenarios: 25 highest burden countries

Value in 2015 (% reduction)
367,000
138,000 (60%)
95,000 (73%)
72,000 (79%)

Mahy et al.
We know more, doing better

• Improved (opt-out) and expanded (community-based) testing
• More efficacious PMTCT drugs
• Expanded treatment for women and children
• Better coverage, less transmission
• Breastfeeding protected
• Push to integrate with NMCH, SRH
So much achieved, so much to do

Percentage of pregnant women with HIV receiving antiretrovirals for preventing mother-to-child transmission of HIV in low- and middle-income countries by region, 2004-2008

The bar indicates the uncertainty range around the estimate.

The disparities among rich and poor women using ANC services and health facilities for child birth are same for integrated PMTCT services.

The poorest women are substantially less likely than the richest women to deliver with the assistance of a doctor, nurse or midwife.

Percentage of births attended by skilled health personnel

Note: Estimates are based on more than 70 countries with available data (2003–2009) on skilled attendant at delivery by household wealth quintile, representing 89% of births in the developing world. Source: UNICEF global databases, 2010.
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

- No of women attending ANC
- No of women tested
- No of women who receive their results
- No of women who receive ARV/ART
- No of babies tested, treated
- No of women tested, treated
  - Number of families followed up
Patient Cascade: Retrospective Cohort in Gilgil Hospital, Kenya (Ferguson et al 2010)

78/236 (33%) attended HIV clinic within 3mth of diagnosis
Of whom:
• All attended within 1mth after diagnosis

25/236 (11%) assessed for HAART eligibility within 3mth of diagnosis

9/25 (36%) CD4<350
Of whom:
• 1 started on HAART within 3mth of diagnosis
• None during pregnancy

Ouch! Ouch!
Stringer, E. M. et al. JAMA 2010;304:293-302

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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.
Impact of 2-tier prophylaxis (sdNVP/AZT) and ART based on reported system performance (KZN)

In PMTCT programme

100 HIV+ mothers

attend ANC clinic 92%

Counseled and tested for HIV, CD4 75%

get ARVs (pre- and perinatal) 50%

0.7 infants infected (2.2% transmission)

Outside PMTCT programme

8

32

66

16.5 infants infected (25% transmission)

Pop. 6wk transmission = 17.2% transmission
Impact of 2-tier prophylaxis (sdNVP/AZT) and ART at 95% system performance

In PMTCT programme

100 HIV+ mothers

attend ANC clinic 95%

Counseled and tested for HIV, CD4 95%

get ARVs (pre-and perinatal) 95%

95

90

86

1.9 infants infected (2.2% transmission)

Outside PMTCT programme

5

10

14

3.5 infants infected (25% transmission)

Pop. 6wk transmission = 5.4% transmission
Coverage and health-seeking behavior

Scenario 1

- Burundi: 16%
- Ghana: 19%
- DRC: 8%
- Angola: 23%

Scenario 2

- Nigeria: 0%
- Ethiopia: 86%
- Chad: 8%

Legend:
- GREEN: ANC 1+
- RED: HIV test & ARVs available in ANC facilities

Marginalized groups

- Support marginalized women to:
  - access services
  - adhere to prevention and treatment
  - return for follow-up
- Ensure their children receive services
- Protect from victimization
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
Promote child development

- Knowledge, support, assistance for:
  - Good nutrition in pregnancy, early childhood
  - Immunization and health care
  - Care for development – play, language
  - Reduction of harsh punishment
  - Child care and protection
  - School readiness, support for schooling
“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
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
• 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
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 Ghys, Marjorie Opunji, David Barr, Ramzi Alsallal, Lori Bollinger, Marcelo de Freitas, Geoffrey Garnett, Charles Holmes, Ken Legins, Yogam Pilley, Anderson Eduardo Stanciule, 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.
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 - other 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