“The Road to Washington”
Ensuring common ground in mobilizing communities to create a supportive environment to help end paediatric HIV and to support families

London

Linda Richter

28 February 2012
The Road to Washington ....
Most significant and substantial commitment to children and families since the start of the epidemic

Alive with opportunities ...
The Concept of Zero Child HIV

Massive, public, accountable commitment to children

Needs a huge, comprehensive effort
To Achieve Targets ...

Expanded, better-resourced health services with:

- Large scale efforts at stigma reduction
- Involvement of affected women and their families
- Increased demand & barriers addressed
- Follow up to ensure wellness
- Use of PMTCT as an entry point for wider services
Community Action Good At:

- Transmitting key messages – especially to hard-to-reach populations
- Influencing & supporting hold norms and behaviour
- Increasing access to services as go-betweens
- Providing stop-gap and complementary services
- Holding health services accountable
CCABA Actions

- Geneva Meeting May 2011
- Addis Meeting December 2011
- JIAS Special Issue
- Pamphlet to support community action
- Partnerships and collaborations – eg IATT CEWG
- London Meeting February 2012
- Washington activities July 2012
Some Reminders
Cascade, not a funnel

Everyone gets services as required, each step of the way.

Many need help, but fewer served, and even fewer benefit.
Patient Cascade: Retrospective Cohort in Naivasha Hospital, Kenya (Ferguson et al 2010)

42/155 (27%) attended HIV clinic before 3mth after delivery

26/155 (17%) assessed for HAART eligibility

12/26 (46%) CD4<350

Of whom:
• 3 started on HAART

Ouch!

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!

Slides from Ryan Phelps and Ade Fakoya
Losing children: The HIV Care Continuum

PMTCT Programmes & ANC

- All pregnant mothers
- HIV positive mothers
- ~½ have no PMTCT access
- Attrition of mothers from PMTCT programs

Paediatric HIV Care

- HIV exposed infants
- <1 in 10 HIV-exposed infants tested in first 2mo
- HIV-infected children
- Attrition of children during pre-ART process
- Most attrition on ART in the first year

Adolescent/Adult Care

- Transition into adolescent & adult life-long treatment and care
- Substantial attrition with transitioning to adult care

Slide from Ryan Phelps
Narrow Targets - What About ...  

- Women’s survival and health?  
- Infant growth and development?  
- Partner detection and treatment?  
- Family support?  
- Assistance for ongoing adherence, prevention?  
- Couples’ reproductive choices?  
- Co-infections eg TB
What “Community” Can Do

• Hold leaders accountable - vision & action
• Advocate / demand:
  • Comprehensive, equitable quality services
  • Test and expand promising practices
• Improve community knowledge & norms
• Help marginalized groups access services
• Support women and families
“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
Role Not Recognized

- “Sidelined, siloed and silent”
- Cut-off from:
  - prevention (young people, PMTCT)
  - treatment (adults and children)
  - care and support for families and
  - palliative care
- Role in epidemic diminished, unrecognized, under-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
How Best To Hold Hands?

Health services and systems

Community action (especially OVC groups)

Wellbeing of children and families
Scenario 1

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

Scenario 2

- Nigeria: 58%
- Ethiopia: 86%
- Chad: 39%

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 69% of births in the developing world. Source: UNICEF global databases, 2010.
Summary Demand-side Barriers to Uptake

- Transport, food, medical costs
- Lack of knowledge
- Misconceptions
- Fear rejection by partner and other family/friends
- Stigma

Summary Demand-side Opportunities

- **Reduce/remove associated costs** - Evidence exists for CCT...less for other such as transport vouchers, food supplements
- **Mass Media** – few (no?) good studies demonstrating influence in regard to uptake of pediatric HIV testing and care; need formative research - which messages resonate with women and their partners?
- **Integration with ECD** – need to better understand demand - what array of services work?
- **Mobile** – promising but coverage across rural poor women presents big challenges needs to considerably improve
Prong 1: Percent of male partners who received counseling and testing, 2008

- Need stronger male involvement and couple counseling programs

- Global (57 countries): 5
- Rwanda: 77

Slide from Karusa Kiragu
An Ermelo man who allegedly whipped a woman to death with a sjambok was arrested on Tuesday. Mpumalanga police said. The 33-year-old man allegedly whipped Ellen Nkosi to death at about midnight on Monday. Police said he shouted at her for not breastfeeding her baby to make it stop crying, and then whipped her.”
What Did We Hear?

• Examples of very large scale programmes integrated with formal health services
• Innovations eg male involvement, partner tracing
• Voices of affected groups
• Push for human rights
• Generally at the programme level
Slides from Mitch Besser

<table>
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<tr>
<th>Current Date</th>
<th>March 2011</th>
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<tr>
<td>Sites</td>
<td>714</td>
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<tr>
<td>Field Staff</td>
<td>1765</td>
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<tr>
<td>Patient Encounters Per Month</td>
<td>263,817</td>
</tr>
<tr>
<td>New HIV-positive Women Per Month</td>
<td>23,680</td>
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Community Services that impact the CBCHB PMTCT Program in Cameroon

- CBCHB is a community-based organisation running 5 big hospitals, 25 integrated health centres and about 50 primary health centres in six of the ten regions in Cameroon.
- Community based – present in few urban cities and mostly in the remote parts of the regions
- Mission of CBCHB is to provide care to all who need it as an expression of Christian love.
- CBCHB has been running PMTCT since Feb 2000 and has reach over 600,000 pregnant women with counselling and testing through 452 sites with support mainly from EGPAF.
- Major program challenges include low uptake of prophylaxis, low follow-up of HEIs, poor male involvement, stigma & discrimination.

- August 2007 – Dec 2010, identified 6,642 index persons
- 5,271 of their contacts traced and notified, 3,977 (75.4%) tested and 2,154(54.2%) tested HIV positive. 60.8% of those tested positive enrolled in care.
Number of children tested for HIV Jan-Dec 2010

- Jan: 30
- Feb: 10
- Mar: 30
- Apr: 43
- May: 51
- Jun: 45
- Jul: 39
- Aug: 64
- Sep: 64
- Oct: 59

Slides from Stanley Kiplangat
MAMA+

Comprehensive Support to HIV-positive Mothers with Young Children

- Social workers
- Psychologists
- Medical providers
- Educators
- Lawyer
- Peer counselors

Slides from Roman Yorick
Network Support Agents - Uganda

- 1,300 network support agents operated in 40 districts in Uganda to link community to health services.

- 1.3 million people accessed HIV services and 19,832 vulnerable children were referred for services as a result of the work of the network support agents.

- In one district PMTCT services increased from 1,264 in 2008 to 15,892 in 2009

The way we work in the clinic and the community

- Network Support Agents spend 2 days at the clinic and 3 in the community.

- I work with 98 people and 20 families
Vital Voices

Learning from the experiences and perspectives of people living with HIV to inform PMTCT programmes and health facilities/services

Summary of Recommendations

- Education of health care providers on how to provide non-judgmental support to PLHIV accessing PMTCT services;
- Provision of accurate information to PLHIV and their partners and recognition of individual right to test for HIV;
- Peer support as part of post-test counseling and PMTCT programming;
- Support for safe conception and healthy pregnancies;
- Continued consultation and operations research with people living with HIV to ensure policies and programmes are responsive to the needs and experiences of people living with HIV.
Secondary traumatisation and coping strategies of HIV positive women working with other HIV positive women.
What Is Less Apparent

• Translation of high-level commitment into implementation plans and strategies

• Monitoring, reporting, accountability of community plans

• Media, messaging, materials – at all levels
2007 WHO, UNICEF, IATT et al

8. Empowering and linking with communities

1. Define a standard package of interventions to be provided by CBOs
2. Establish district-wide systems to link services to CBO providers
3. Build capacity and provide technical & financial support to CBO providers to deliver interventions to support PMTCT and HIV care for children in services & community
4. Promote active participation of affected groups
5. Promote & support male-friendly models & participation of men
6. Policies and programmes to address stigma, violence etc

GUIDANCE ON GLOBAL SCALE-UP OF THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV
Towards universal access for women, infants and young children and eliminating HIV and AIDS among children
2011 UNAIDS et al
Call for greater community engagement

Community Leadership Actions. Communities will ....
1. Develop community charters – by May 2012
2. Ensure participation of all stakeholders
3. Maximise community assets
4. Identify solutions to stigma

Build community capacity to monitor progress
US$ 1b between 2011-2015

This includes costs for HIV testing and counselling, CD4 counts for pregnant women testing HIV-positive, antiretroviral prophylaxis, antiretroviral treatment and co-trimoxazole for eligible women and children, family planning for women living with HIV and community mobilization. The annual requirements in these 22 countries are estimated to
Countdown to Zero also recognises the importance of communication

Communication priorities
1. Gain public support for the campaign
2. Mobilise couples to take up services
3. Reduce stigma & discrimination

- Who and what needs to be addressed
- Sharing practices
- Communicating with communities
Integrative Reviews

• Promising practices in community engagement for elimination of new HIV infections in children - Gulaid & Kiragu UNAIDS (2011-)
• A review of intervention models and evidence – Busza EGPAF (2011-)
By logic model, depth of engagement and level of social processes
Family-centred services for children affected by HIV and AIDS

Guest Editor: Linda Richter
Supplement Editors: Susan Kippax and Shirin Haidari

Contents

- Editorial: Preparing services for children affected by HIV and AIDS through a family lens
  Linda Richter, Chris Boyce, Susan Kippax and Shirin Haidari

- An introduction to family-centred services for children affected by HIV and AIDS
  Linda Richter

- Family-centred approaches to the prevention of mother-to-child transmission of HIV
  Thomas S. Belamoust, Elshwai A. Abozien, Aminah Baid and Mary C. Smith-Pench

- Lessons learned from family-centred models of treatment for children living with HIV: current approaches and future directions
  Sarah C. Leppe, Brian T. Montague, Jennifer F. Friedman and Timothy P. Flanagan

- Fathers and new considerations for families
  Lorraine Shear

- Data availability on men’s involvement in families in sub-Saharan Africa to inform family-centred programmes for children affected by HIV and AIDS
  Victoria Nkomo and Siphiwe Nkubani

- Children of female sex workers and drug users: a review of vulnerability, resilience and family-centred models of care
  Jennifer Swart, Godfrey Siyabhe, Mohamed T. Brooks, Jill Costello, Mark Cornishman, Megan Brewah, David Byno and Jonathan L. Simon

- The impact of HIV and risky behaviors on the lives of married men who have sex with men and inject drug users: Implications for HIV prevention
  Seth D Solomon, Shaima Hameed, Amanda Ladmore, Ayiku Korkoah and David D. Celentano

- Family-based HIV prevention and intervention services for youth living in poverty affected contexts: the CHAMP model of collaborative, evidence-informed program development
  Ann E. Eron, Mary M. McInerney, Claire Donnelly, Jane Petersen and Carl Bell

- Family-centred HIV interventions: lessons from the field of parental depression
  Mark Tomlinson

The publication of this supplement was supported by Coalitions on Children Affected by AIDS and the Joint Learning Initiative on Children and AIDS.
JIAS Special Issue

Community Action to End Paediatric HIV Infection

- Foreword by M Sedibe and E Goosby
- Note on ‘Language, identity and responses to the HIV and AIDS epidemic – GNP+
- Introduction – Editorial team
- 6-7 papers and short reports
- 800 printed copies (mainly for Symposium)
- 1000 USB cards, also with previous special issues (JIAS Families; VCYS Firelight; AIDS Care JLICA)
Vulnerable Children and Youth Studies: An International Interdisciplinary Journal for Research, Policy and Care

Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/rvch20

Countdown to Zero: Only possible with 100% support for children and families

L.M. Richter a & Lorraine Sherr a

a on behalf of the Coalition on Children Affected by AIDS (CCABA)

Available online: 24 Feb 2012
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 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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This pamphlet was written and designed so that it could be edited and customized by community organizations to suit local needs.
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.
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 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.
Few could have imagined that we’d be talking about the real possibility of an AIDS-free generation. But that’s what we’re talking about. That’s why we’re here. And we arrived here because of all of you and your unwavering belief that we can -- and we will -- beat this disease.

- President Barack Obama World AIDS Day 1 December 2011