“The Road to Washington”
Mobilizing communities to create a supportive environment to help eliminate vertical transmission

Introduction:
Out of the box and into open space

Linda Richter
Why this road ... ?

- CCABA’s mission ... children
- Global focus PMTCT – commitment, opportunity for children, families
- Avert narrowing of goals
- Potential of “OVC community” capacity
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
HIV, families and poverty

- Neglect of children in the epidemic
- Shifting focus from orphans to families
- Strengthening families
  - Social protection
  - Integrated family-centred services

Mexico IAS Plenary 2008

Joint Learning Initiative on Children and AIDS (JLICA) 2008
Social protection

• Expansion of social security in SSA – 26 countries
• Impetus - advocacy on behalf of children affected by HIV/AIDS
• UNAIDS Expanded Business Case: Enhancing Social Protection
Strengthening families

• Acknowledge NB role of families in care of children
• Ensure families have resources
• Assist families to access services
• Provide services in ways that reinforce family care
Family-centred services

- Services are intermittent, family care is lifelong
  - Reinforce family care
  - Accommodate interdependence of family
- Provide services together
- Adapt services to families
- Use entry points to reach members
Family-centred services

• Reviewed benefits for:
  • Children’s ARV treatment
  • PMTCT (+)
  • Care and support for affected children
  • Children of sex workers, drug-users, MSM
Developmental, family-centred approaches
Global focus on PMTCT

- Declarations, acceleration, Global Fund re-programming
- Last 6 months:
  - Nov 2010 Virtual Elimination, Geneva
  - Early 2011 Regional meetings in East/Southern & West/Central Africa
  - 2-5 May PMTCT IATT, Geneva
  - 6-7 May Global Task Team, Jhb
  - 9-10 May PMTCT & community action
Most significant and substantial commitment to children and families since the start of the epidemic

Alive with opportunities ...
Knowledge expanding

Average number of papers on PMTCT (clinical, public health) published per annum

153 papers published in 2010
We know more, doing better

• Improved testing (opt-out)
• More efficacious PMTCT drugs
• Expanded treatment for women
• Better coverage, less transmission
• Clearer feeding options
• Implementation challenges
  • Inclusion, follow-up (too many left out, too many lost)
Ward off narrow targets

- < 5% transmission of HIV from mother to child
- 90% reduction in infant infections
- Measured at ?6 weeks, ?6 months

Even these will be hard to achieve without significant mobilization of all levels of community action.
What happens to …

• 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?
Cascade, not a funnel

Everyone gets services as required, each step of the way

Many need help, but fewer served, and even fewer benefit
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

For example ...

- Young women in Africa with comprehensive knowledge of HIV: 23%
- Pregnant women in LMICs who receive an HIV test: <30%
- At least 1 antenatal visit: 73%
- Unmet need for family planning for HIV+ women: 51-90%
Barriers to success

- Facilities, stock outs, regimens, M&E etc
- Attitudes, opportunities lost, lack of follow up
- Fear of partner response, lack of money, isolation
- Stigma, norms, lack of pressure/demand etc
Consequences, levers

- Too many women still don’t test, receive results, adhere, return
- Too many children aren’t tested, treated, followed
- Too few families benefit

Integration will be driven by demand

Rights, gender, affected grps
Legal recourse, media advocacy
Knowledge, social mobilization
Support, assistance
What can “community” 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
• Promote child health and development
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
Comprehensive, equitable

- Too many of the most vulnerable women and families are excluded
- Poor, rural, marginalized groups (sex workers, drug users)
- Targets – not at the cost of exclusion
Promising practices

• Couples, home-based testing (disclosure, links to treatment)
• 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
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
Community knowledge/norms

• Improve knowledge:
  • Make policy & program changes accessible through media and other channels (eg early anenatal 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

- Families
- Communities
- CBO’s and NGO’s
- International agencies
- Governments

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

• 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 shake hands?

Health services and systems

Community action (especially OVC groups)

Wellbeing of children and families