

# Using Evidence to Advocate for *Our Young Children*

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*Keynote Address*

**Children and HIV: Start Early Start Now – Integrated  
interventions for young children born into HIV-affected families**

Melbourne, Australia

18<sup>th</sup> July 2014

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# Overview

- Journey as a Mother of HIV-exposed children
  - My advocacy work prior to 2013
  - Learnings from—and National-level Actions stimulated by—  
The Coalition for Children Affected by AIDS's 'Road to  
Melbourne' meeting series
  - Opportunities for future advocacy
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**PMTCT interventions: I  
have two lovely HIV-  
free babies**



# **My Background**

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# My Advocacy Work Prior to 2013

- Advocacy on sexual reproductive health and rights of WLHIV-campaign to end coerced sterilization of WLHIV
  - Represent WLHIV at the PMTCT technical Working Group
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# The 'Road to Melbourne' Meeting Series: Meeting #1 – New York

- Invited by The Coalition for Children Affected by AIDS to the first meeting in New York—on the state of the evidence.
  - Learned about the theory and science of early child development, and how linked interventions could achieve great results.
  - Learned that many interventions do not reach or include pre-school children.
  - Early childhood—under 6 years old—is a missed opportunity for the children--and their families. It can break the cycle of poverty, of risk-exposure, etc. because of its tremendous impact on child development
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# Meeting # 1 (Continued)

- Lack of a focus on early childhood has negative consequences for children affected by HIV
  - HIV positive children—and HIV-exposed, uninfected children—likely to experience developmental problems
  - What struck me: Dr. Lucie Cluver's scientific presentation on pathways to child risk (parental AIDS illness and orphanhood)
  - Need to invest in sets of linked interventions and increase the coverage of services for the youngest children.
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# Taking Initiative

- Realized all this science is talking about *my* children. Thus, the need for action
  - ICW Kenya and NEPHAK organized a meeting and mobilized members to reach out to MPs and Senators on eMTCT issues for WLHIV. I attended and raised the needs of children under 6 affected by HIV—based on what I learned at the NY ‘Road to Melbourne’ meeting.
  - Later, I was appointed to the National Steering Committee on Maternal and Child Health. This forum has provided a unique opportunity to champion interventions for young children to policy makers in the country.
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# Taking Initiative (Cont.)

- It provoked a lively discussion on better focusing on affected children—and since then, other stakeholders representing affected children have been brought on board—i.e. the education sector & social protection advocates.
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# ‘Road to Melbourne’ Meeting #2— Cape Town

- Focused on implementers: Promising approaches for *Integrated* programming for children born into affected families.
  - Met implementers working specifically on *integration* in order to reach young children;
  - Catholic Relief Services Malawi presented an innovative intervention—child health days for children below 6 years. Held in a central location within a community for easy access. Different services offered on child health, nutrition, parenting support and hygiene.
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## Meeting # 2 (Cont.)

- Children of sex workers and other key population face unique challenges and stigma—sex workers should be supported during pregnancy and after to improve their health outcome.
  - Shining Hope for Communities (SHOFCO) in Kibera, Kenya, integrates health, education and economic development to respond to the needs of children affected by HIV. They demonstrated how economic empowerment improves living standards of affected children.
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## Meeting # 2 (Cont.)

- Isibindi home visiting programme in Kwazulu-Natal, South Africa uses Child and Youth Care workers to do stimulation of young children, to improve child development
  - HOPE Worldwide's ECD parenting training program should be essential for mothers living with HIV
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# Taking initiative

- A community based organization that we founded— Personal Initiative for Positive Empowerment (PIPE)—had never focused on young children, only on mothers.
  - After the Cape Town meeting, it was clear to me that there was an opportunity for PIPE to do more. I went to speak to them. They're now targeting children of infected members.
    - Psychosocial support groups and activities for young children
    - I am discussing with them the introduction of parenting support
  - Because there was a lively discussion in Cape Town on the importance of skilled, trained support, I've been working with NEPHAK to advocate for structured engagement of Community Health Workers (CHWs) -Paying for their work in the community
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# 'Road to Melbourne' Meeting #3 - London

- Reviewed the findings of the first two meetings, and discussed advocacy—getting the word out about the research, and the promising interventions.
  - Advocacy messages were discussed, including *The Melbourne Statement* produced by The Coalition for Children Affected by AIDS—which is in your symposium packages
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# Taking initiative

- I've continued to think of how I can be an advocate for integrated interventions that support the youngest children. Since the London meeting:
    - Kate Iorpenda has linked me with a Hilton-funded program at Kenya AIDS NGOs Consortium (KANCO), which is starting to work on early years issues. We are seeing what we can do together; and...
    - I received training on the *Essential Package on Early Child Development*—which is the subject of a workshop here at this symposium.
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# Opportunities

- What are the obvious opportunities for you to take forward the messages and evidence from this symposium, and change your community, your organizations, your programs, your policies?
  - **If you are from the community**, you know that this work needs to be done. These are our children. Even if no more money comes our way, this is the right thing to do.
  - **If you are a funder**, you need to fund community-based interventions that support us and our children, and that translates the research I heard and gets it down to the community.
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# Opportunities (Cont.)

- **If you are from a government ministry**, work towards integrating services, to meet the needs of children affected by HIV and their guardians
  - **If you are from a multilateral organization**, support governments and communities technically and financially to *ensure adequate and sustained programming for our young children*
  - **And to The Coalition for Children Affected by AIDS**, there is need to reach out to more players, sensitize on the need to focus and prioritize on the early years.
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**THANK YOU!**

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