

PLENARY 2B

Invisible children seen through the lens of HIV/AIDS

by Adrienne Blomberg

SIAM-CARE THAILAND

1. Invisible children seen through the lens of HIV/AIDS? How are they invisible? We see them around us all the time; yet millions of children are affected by HIV. Recently a friend sent me a book on the 'Heroes of the Faith' series. This particular book was about a hero of mine – Mother Theresa. Towards the end of the book, it states: *'The sly humor and the joy were now invisible in her creased face.'* I read it again and the light bulb turned on. This book had come just in time when I was asked to speak at this plenary. Mother Theresa was still alive and visible, but who she really was had become invisible. So it is with children. Yes, we see them but who they really are has become invisible – their joy, their childhood, their healthy bodies, their longings have become invisible. This is where our challenge lies – to bring that what makes the child the little person created in God's image come alive again. It is said that 230 million HIV viruses would fit on the tip of a pin, yet a normal microscope cannot detect it. Even with highly specialized equipment, it would still need a trained eye to find the virus. So it is when we work with HIV-affected children, we need to look very carefully, very accurately and also stay committed to the long haul. For only then can we see that what is invisible, hidden in the physical, emotional, social and spiritual aspects of the child. I hope that through this short presentation, I can help you a little on your way.

2. HIV is really very new. If we go back 100 years, we would find children affected by poverty, disability, wars etc but not HIV. Just to make something very clear right at the start, HIV stands for *Human Immunodeficiency Virus* while AIDS stands for *Acquired Immune Deficiency Syndrome*. Someone who lives with HIV does not necessarily have AIDS, in fact there are probably many in this world who are HIV positive (meaning they carry the virus in their bodies) but do not have AIDS. It is important that you know the difference and are careful in how you use the terminology. It can be very insulting to say that someone has AIDS when in actual he or she only has HIV in their bodies. Do you know what you live with in your body? Most of us carry germs around and we would not want to be branded a name because of it.

3. How long has HIV been around? Let's have a quick look at some of historic facts:
 - 1981– Medical researchers around the world became aware of a frightening new disease. They rushed to understand how the new disease was spreading and how it could be stopped. As they gathered clues, they searched for patterns that would explain who is at risk, and why. Several healthy young men suddenly develop a rare, fatal pneumonia and cancer that's almost never seen in younger men, They are almost all young homosexual men.
 - 1982 – Doctors report that a few injection drug users, who sometimes share needles, also show signs of the new disease. Among the latest cases are infants of women who are injection drug users.
 - There are reports of people with hemophilia getting the new disease.
 - US health officials begin using the name *Acquired Immune Deficiency Syndrome* or AIDS to describe the new disease.

1983 – At the Pasteur Institute in Paris, researcher Luc Montagnier reports that his lab has found a virus linked to AIDS.

Researchers have identified several groups at risk for getting AIDS.

1984 – Robert Gallo, scientist at the US National Cancer Institute, reports that his lab has isolated the virus that causes AIDS.

A test to detect the virus that causes AIDS is approved in the US.

1986 – World scientists agree on the name *Human Immunodeficiency Virus* or HIV for the virus that causes AIDS.

1987 – AZT, the first anti-HIV drug, is approved for experimental use by the US Food and Drug Administration (FDA).

1990's – Many celebrities come out in the open acknowledging that they have AIDS e.g. Michael Jordan, Arthur Ash.

Today, AIDS is reported in almost every country around the world. The world epidemic (pandemic) of HIV is growing at an alarming rate. As public health officials work to spread prevention information, scientists are racing to better understand HIV/AIDS.

So, we are really only aware of HIV for ¼ of a century. From the time the name AIDS was given in 1982 up to now, it is exactly 25 years. And what has happened since?

4. I like to present some statistics. We all know that statistics are only numbers and don't tell a life story. Yet they can alert us to the severity of a situation. Statistics should be used together with a mind that is open to analyze and understand and also a heart that is open to be moved by the lives behind the statistics. Statistics should be critically looked at to find out what they tell us and what they fail to tell us. No one has ever been moved by statistics to take action, the heart is moved by lives, and passion comes from seeing lives hurt. Passion is what is needed to act. If I were to ask you why you do the work you do at present, in whatever area you work, I do not think anyone would answer, "Because I saw statistics." More likely I'd get the answer, "Because I was touched by the live of one child I met when..." Still it is good to look at statistics and to see what the world bodies and governments are trying to do.

To name just a few facts:

- 65 million people have been infected. 25 million already died. Of those alive, estimated 4 million are < 15 years.
- More than 13 million children under the age of 15 have been orphaned by HIV/AIDS, and this number is projected to double by 2010.
- Children born with HIV in 2005 - 540,000
- By this time tomorrow, 8,000 people will have died of AIDS. Many of them will be children
- 90% of all infected live in the developing world:
 - 842 million people worldwide suffer from chronic hunger
 - Children who drop out of school are 3x more likely to become HIV infected than peers who complete their basic education.
- ARV (anti-retroviral) available to 1 in 5 who need it
- An estimated 10.3 million young people age 15-24 are living with HIV/AIDS.
- Half of all new HIV infections – almost 6,000 infections per day – occur among young people.
- Grandmothers are at the frontlines of the AIDS epidemic (2/3 in Thailand)
- Children are affected by HIV/AIDS in a wide range of direct and indirect ways, all of which jeopardize their basic rights.

5. Have a look at the world map. We need to remember that most of those infected are aged between 20-40 with a shift going to younger infection even. We see the hourglass effect. The world's most affected country is Swaziland with 34% prevalence in the general population while 43% ANC. The United Nations (UN) will tell us that a country with a prevalence of over 1% is at risk of losing control over the situation.
6. So what has the world done? What was the response of the UN? In 1995, UN sets up UNAIDS with Peter Piot as its head from the start up to this day. In 2001, Global Fund was established to activate countries to pledge extra funds to fight Malaria, TB and HIV. Individuals like Microsoft king Bill Gates started their own foundation. As wonderful as all that is, it treats the masses; it gives us our statistics, mass campaigns, provides much needed medication, but often the small ones fall through the maze. Yet, these are lives created in God's image that have importance. I believe that we as Christian workers, Christian organization should seek out those who miss out.

At the 2001 UN General Assembly, leaders from 189 member states agreed to a declaration of Commitment on HIV/AIDS: "Commitment to deliver HIV prevention, treatment, care and support in order to halt and begin to reverse the global epidemic by 2015."

- 90 % of youth (15-24) who correctly identify prevention methods Male 33% Female 20%
- 80 % of HIV pregnant women on ARV: 9%
- 50% of PLWH needing ARV (3/5) 20%
- 20 % reduction of youth (15-24) infected: Male 1.4% Female 3.8%
- 20 % reduction of infected newborns: 10% (26% are infected)

7. So, here we are with overwhelming statistics but are they really that overwhelming? Let's take malaria for example. Each year, malaria causes at least one million deaths and an additional 300 – 500 million clinical cases, the majority of which occur in the world's poorest countries. More than 41% of the world's population is at risk of acquiring malaria, and the proportion increases yearly. So, why the emphasis on HIV?

The difference with HIV is that it affects a much wider range:

- It affects the person who is infected themselves, of course.
- It affects families – Mostly more than one in the family is infected, so it also affects others physically and more so, caregivers and those left behind. In 2004, approximately 1.2 million women and 510,000 children under the age of 15 died of AIDS-related causes.
- It affects communities – parents die (hour glass effect), income for the elderly and children disappears.
- It affects nations – the well educated ones die, agricultural workers die (workforce is depleted)

8. Now, let's look more specifically at Asia. East Asia is now home to the fastest growing epidemics in the world. Thailand, Cambodia and Myanmar all have generalized epidemics. Papua New Guinea is heading towards a severe epidemic most closely mirroring the epidemics found in the sub-Saharan Africa while Timor and the Philippines are still experiencing very low prevalence. Many of the 580 million children currently living in East Asia and the Pacific experience vulnerability from one or more causes including: poverty, violence, sexual exploitation, abuse, malnutrition and migration.

- Asia: 8.3 million people infected (2.4 million women – globally 50%)
- ARV available to 16% of those who need it

Data collection on children and HIV/AIDS is not well developed – Asia and the Pacific (2004):

- 1.5 million orphaned by AIDS
- 120,700 children living with HIV

- 46,900 newly infected in 2004
- 35,000 needing ARV

	<i>Cambodia</i>	<i>India</i>	<i>Thailand</i>
Estimated population growth	14 millions	Billions	64 millions
	2%	1.6%	0.9%
Living on <2 \$	77.7%	79.9%	32.5%
Government expenditure (per capita) on health	\$36	\$20	\$160
HIV prevalence in adults	1.6%	0.9%	1.4%
# of adult cases	130,000	5,600,000	580,000
Children with HIV	NA	NA	16,000
Pregnant women on ARV	1.4%	1.6%	30.6%
% of positive people receiving ARV	36%	7%	60%

9. With all the declarations, mega funds, commitments etc. why is it that HIV is not yet under control? In Africa, it is the leading cause of death and it is the fourth worldwide. So, what is it that drives this pandemic?

The human biology:

- Immature genital tract
- Pregnancy/MTCT
- Stage of HIV in sex partner
- Malnutrition

Human behaviour:

- Unprotected sex
- Multiple partners
- Early onset of sexual debut
- IVDU and alcohol abuse
- Abusive behaviour

Cultural practices:

- Student initiation
- Dry sex and other risky practices

Social environment:

- Poverty
- Migration
- Child trafficking

10. It is high time we look specifically at the children now. How is it that with this immense problem we call them invisible? Our vocabulary already created invisibility. For example, when a child who is born to an infected mother but is not infected him/herself, we say the child is 'lucky'. However, if the child is infected, we call him/her as 'pitiful'. In giving a name that covers up what the child needs, we create invisibility.

Infected:

- During pregnancy
- During labour when lots of body fluids are around
- Breastfeeding
- Child abuse

Affected:

- Physically
- Emotionally
- Socially
- Spiritually

11. Physically

- Nutrition
- Immunizations
- Treatment for OI
- Hygiene
- ARV (adherence: 5R)

12. Emotionally

- Hugging/holding
- Age appropriate activities
- Teenagers starting relationships
- Talking/listening

13. Socially

- Interaction with friends
- Education
- Protection from stigma and abuse
- Breadwinners
- Caring for sick parent or the elderly

14. Spiritually

- Why me???
- Who to go with?

15. If we want to make the invisibility visible and work with/for the child we need to work:

- With the (extended) families
- With the GOs (schools, hospitals etc)
- With other NGOs
- With the children

Never give up

Never give in

Never rush

Yet

We should run

For

We are running out of time!

16. May God bless us with discomfort... at easy answers, half-truths, and superficial relationships, so that we may live deep within our hearts. May God bless us with anger... at injustice, oppression, and exploitation of people, so that we may work for justice, freedom, and peace.
- May God bless us with tears... to shed for those who suffer from pain, rejection and sickness. So that we may reach out our hands to comfort them, and to turn their pain into joy. And may God bless us with enough foolishness... to believe that we can make a difference in this world
- So that we can do what others claim cannot be done. Amen.

Research for this paper was done by reading the following publications and websites:

1. *The truth about Aids (Dr Patrick Dixon)*
2. *Micah network Malaysia 2007 (presentations by: Dr Peter Okalet, Steve Bradbury)*
3. *Pediatric HIV infection (Arthur J Ammann)*
4. *Publications by Save the Children UK "Small also have something to say" "Handbook for community health workers"*
5. *UNICEF publication: "Scaling up the response for children"*
6. *Pediatric HIV infection (Arthur J Ammann)*
7. *"Brenda has a little dragon in her blood" by Hijtlje Vink*
8. www.aidsmap.com
9. www.unicef.org
10. www.unaidsf.org
11. www.womenchildrenhiv.org
12. www.thebody.com
13. www.avert.org/aidsthai.htm
14. www.theglobalfund.org