

Orphans and HIV: The Second Wave of the HIV Epidemic

"Global Strategies for the Prevention of HIV Transmission from Mothers to Children"

Montreal, 5 September 1999

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In our global world today, women and children do not come first. And if they are poor, they come last. Orphans lose the advocacy of their parents for their rights specified in the UN Convention on the Rights of the Child. And society has a poor record as advocates for the rights of orphaned children.

In 1988, I read an interview given by the late Jonathan Mann in the Herald Tribune where he said that by the year 2000, AIDS was going to create "cohorts of orphans," many of whom would be infected with the disease. I was just beginning to get my life together after the death of my son, and was establishing the Association François-Xavier Bagnoud. I wanted to use my resources to rescue children not cared for by others. Jonathan's declaration made me choose to put the focus on those children. Children don't vote; they cannot lobby for themselves. And at FXB, we are committed to forgotten people in forgotten places.

In the very early stage of the AIDS pandemic I established François-Xavier Bagnoud Houses where a small number of children without parents and suffering from AIDS could live in a family setting and receive tender loving care until they died. The Association allocated significant resources to these houses to show the world how important it was to take care of these children in need and give them the best love possible during their short lives. Quality, the best, where there was limited quantity of time. These houses are living statements against discrimination.

Fear and prejudice were not the only characteristics of the early stages of the pandemic. Ignorance and denial were also prevalent. In the early 1990s, the Association supported Jonathan Mann's effort to provide an accurate description of the AIDS pandemic after he left WHO. When he released his findings in mid-1992, explaining how widespread AIDS would become by the year 2000, it made the front pages of newspapers worldwide, but brought denials by WHO which still refused to acknowledge the extent of the pandemic.

It is ironic and sad, that seven weeks ago, The New York Times published an interview with Peter Piot of UNAIDS saying that the criticism aimed at Mann in the early 1990s had come full circle. Then, WHO criticized Mann's figures as excessive. Now, UNAIDS and WHO whom Jonathan had inspired to change were being criticized by academic scientists for again exaggerating the extent of AIDS in Africa. "When we look at the figures today, they are worse than Jonathan published," said Dr. Piot.

And I think that we are making similar mistakes today especially in India, a country I have been working in for 10 years. Two years ago, the infection rate in that country was estimated to be less than 1%. But taking estimates of the rate of the spread of the epidemic from "AIDS in the World" which the FXB Center published in the early 1990s, I am suggesting that the rate is at least 4%. That would already be 40 million people infected. What surfaced in Sub-Saharan Africa will soon produce the same cruel picture in India, when countrywide testing starts there.

UNICEF itself admits that for ten years it didn't or couldn't collect data on orphans. Meanwhile,

- Worldwide, a very conservative figure from UNAIDS says that more than 8.2 million children have lost their parents to AIDS. And over 90 percent of those orphaned live in Africa.
- But in sub-Saharan Africa, by 2000 – that is less than four months from now — according to other serious sources, the number of orphans will reach 13 million, 10.4 million under the age of 15.
- In 35 countries, the rate at which children are orphaned doubled, tripled and even quadrupled between 1994 and 1997. In 1997 alone, 1.6 million children were newly orphaned by AIDS.
- Fears are that Asia will see its orphan population triple by next year. Again in a few months.
- And one in every three children orphaned by HIV/AIDS is under age 5.
- Sometime between the year 2010 and 2020, the global number of infants and children under

15 who have lost their mother or both parents to AIDS will reach 40 million, the size of the population of a country like Colombia.

There is no “second wave” of AIDS orphans as such. We are still fully immersed in the first wave that spreads silently and which has become a tidal wave and increases in devastating force. The second wave is the shocking fact that rich countries have mastered the epidemic mostly by drugs, while in the poor countries death is spreading like bad weeds thriving among financial and political neglect.

On our shrinking planet, in our global family, at the end of this millennium, the children are awash in misery.

- 12 million children under 5 years of age die each year.
- 30 percent of all these deaths are linked to starvation and malnutrition.
- Nearly 160 million children are malnourished.
- More than 250 million children are working as child laborers.
- Next year, there will be 120 million orphaned or abandoned children. And 100 million will be struggling to survive on the streets of our mega cities.
- 650 million children, at least, live in abject poverty, with less than one dollar a day.

How can we begin to protect the orphans of the first wave and confront the so-called “second wave of the epidemic” unless we begin to respect the rights of these children to have the basic necessities for existence: clean water, food, shelter, health care, education? The powerful tools developed by Jonathan Mann and his team at the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health are essential here. It was the AIDS pandemic which lead us to see the inextricable connection between health and human rights. Families deprived of their rights – to food, clean water, medical care, to education, training, to protect themselves from violence and sexual abuse, to vote for their leaders – were the people most likely to be stricken hardest by HIV and AIDS. The people stigmatized and discriminated against because of AIDS demonstrated the validity of the Health and Human Rights paradigm. By implementing human rights, we take the first essential steps to promoting the health of the poorest populations in the world, and attacking the roots of poverty. Health is by itself one of the government obligations signed and ratified by countries in the Convention on the Rights of the Child – article 24.

To see how visible this is just look at sub-Saharan Africa. It is the poorest region of the world and it is the most devastated by AIDS. Of the 14 million persons who have died of AIDS worldwide, more than 11 million have been Africans. This region of the world represents about 60 percent of the world's total HIV infections and almost 90 percent of the current HIV infections in adults and adolescents in Africa itself. AIDS killed 1.4 million people in eastern and sub-Saharan Africa last year, surpassing armed conflict as the number one killer.

Not surprising that according to UNDP, these countries have the lowest standards of living in the world. And life is getting shorter and shorter in the sub-region, with life expectancy decreasing by 5 to 10 years, over the next ten years, in countries like Malawi and Zambia. Men and women are dying at the ripe old age of 40.

Children orphaned by AIDS suffer another load as they watch their parents grow weaker and weaker from the disease until they waste away and die. Often they alone care for their parents, and suffer that they do not have simple medications to ease the loved ones pains.

Often after the death of their parents, these children face prejudice and neglect at the hands of their guardians or communities, or they are shunned by their community that fears they have the virus too. Experience tells us that orphans have frightening higher rates of malnutrition, stunting and illiteracy. At times relatives exploit them by taking their meager inheritance.

These children often have to bear heavier workloads and may be treated more harshly than the foster family's own children. They are less likely to go to school and more likely to be depressed. Young girls are especially vulnerable to sexual exploitation and abuse and lack of equal access to education. And the orphans of the HIV/AIDS pandemic are all too often much more vulnerable to HIV infection itself, which expands the impact of HIV/AIDS on families and fuels the epidemic.

As I traveled the world this past decade developing the programs of the FXB Association, I confronted many sad situations like the above. I also became aware that in some cultures, the way I was rescuing some of these children through setting up FXB houses was not always the adequate solution for all children orphaned by AIDS – whether or not they were suffering from the disease. That was obvious in Africa where the acknowledged numbers were far too great and the culture had the deep-rooted tradition of extended family. In Uganda, for example, child orphans were frequently cared for by members of their extended families, often grandparents. So in that country, the Association took a different direction to provide care for thousands of such children.

We started a modest program to provide the necessities for children orphaned by AIDS. We helped families who had taken in orphaned children to set up small businesses to support the additional burdens that they had assumed. This enabled them to barter goods and services to local schools to pay the children's school fees. This took place in three communities in Luwero, Uganda, where there were about 7800 orphans, 51 percent of whom had lost their parents to AIDS. We helped set up more than 800 income generating projects for these guardian families, and extended the project schools. To date, 3200 children have been enrolled in 51 schools. Thirty-four schools have added classrooms, teachers, and supplies from the proceeds of these micro-enterprises. One school constructed a new tin roof from the funds made available, giving students, teachers and the local community another way to secure precious water from the rains. These children are not depressed; they are not violated sexually; and they are learning the tools for a productive human life. And the families who have taken them in have been rewarded by the smiles of the youngsters and additional secure income for themselves.

I mention this effort for it can be replicated worldwide wherever there are orphans, from the 1.1 million in Uganda, to the 520,000 in Tanzania to who knows how many in India, and how many there will be when the extent of the epidemic is acknowledged. Large sums of money are needed to help these young children, as well as the sensitivity to do it in the proper manner, getting the input of concerned communities as to the best ways of going about it and reevaluating the project by a continuing dialogue.

The basic necessities of these children for a roof over their heads, sufficient food to nourish them, and clothing that is suitable to their communities as well as education should be taken care of.

Programs must also address the psychological traumas and stress that these children have experienced upon the death of a parent, or which come from their living alone for long periods of time. The highest priority is to treat any catastrophic illnesses affecting these children. They should receive the best health care available to treat chronic diseases that have gone unattended. Finally, they should have access to the simple joys of childhood and love.

To help communities provide for the increasing numbers of orphans, new approaches are needed. Normally, the extended or immediate family is the most appropriate environment for the child. When that is not available other families can care for the child supported actively by community involvement.

However, neither the extended family, itself often severely neither affected by AIDS, nor existing institutions are the complete answer for the growing numbers of children surviving after the death of one or both parents. Other options should be developed by the wider community.

For example, now in our FXB House in Barranquilla, Colombia, neighboring families devised their own ways to structure the care of the children with HIV/AIDS where previously there were fear and ignorance. And in South Africa, the government subsidizes the training of foster parents to care for children and infants with HIV infection.

Innovative orphan care programs in Zimbabwe, South Africa, Tanzania, and Uganda show that community visiting, involvement and responsibility for these children work well if organized by community peers or opinion leaders.

In some places, village heads have designated land to be cultivated by all villagers to feed orphans and families of those suffering from AIDS related illness.

Church groups have begun orphan visiting programs where women are trained to identify the neediest orphan households in their area; visit them on a regular basis, provide guidance and emotional support, and help with necessities.

In Southeast Asia, the African approach will, however, be much needed because cohorts of orphans will start as in Africa to appear. But I would like to add a footnote for thought In Thailand, FXB spends \$5,000 per child a year in FXB Houses, providing jobs for numerous women at the same time. Yet, a child in a public health environment such as the Suriraj Hospital in Bangkok with no particular tender loving care costs \$4,800 a year,— the same — However, we spend that same amount in Africa for 100 times more children without however including food or medicine. These children have the best basic survival structures, but no access to the best possible quality care on all multiple and complex levels as have children in the family-type care houses, for there are no public health care structures to deliver it.

We must also involve orphan children as active participants in their lives and look to them to help us find the best solution. AIDS orphans in Zimbabwe were asked about their needs, in an initiative called "let the children speak". As the community became more aware of the children's real needs, plans were made to implement the children's suggestions.

For many children who are orphaned due to HIV/AIDS, opportunities to receive information about health, sexuality and HIV/AIDS may be even more remote than for their peers. They become isolated due to discrimination or because they leave school and assume less visible roles in the community. Additional efforts need to be made to include them. These children have

knowledge and experience that can provide valuable insights about the actual conditions, concerns, difficulties and needs of children most affected by HIV/AIDS. Many have demonstrated their courage and abilities while caring for themselves and often for siblings and other family members. They are credible as peer educators because of this first hand knowledge of HIV/AIDS. They must be included as partners.

As we confront this bleak landscape, we do see signs of action. In July, the US Government committed \$10 million for AIDS orphans programs and in a few short days is convening a leadership meeting to chart the outlines of an African Leaders Summit on orphans. On World AIDS Day, December 1, 1999, the UN with support from NGOS and governments will host a conference on children orphaned by AIDS. Business and religious leaders are also beginning to take hopeful initiatives. And South Africa has decided to manufacture much needed but expensive drugs for its people, although international patent law prohibits it. Four women development ministers of Europe have linked and pledged to fight against poverty. By implementing human rights conventions, governments can attack the roots of poverty and effectively fight the AIDS epidemic which, as Peter Piot of UNAIDS states, is spreading three times faster than rates of funding to control it.

The International AIDS Vaccine Initiative (IAVI) stuns us with the following figures:

- \$20 billion spent annually on the prevention, research and treatment of AIDS.
- \$300 million spent on vaccine research of which only \$50-70 million on vaccine products.
- And of that only \$10-15 million for the strains that affect 95% of people infected by AIDS.

Meanwhile, Kenya can spend only \$8 per capita per year on health care and Ethiopia, \$3.

But even when a vaccine is found, the 40 million orphans of the pandemic in 2010, will remain orphans and in this global world, they are our global responsibility. Dr. Kituuka of Uganda put this well at this conference when she said: "The orphan we care for today, might be the leader of our country tomorrow."

There is a stirring of a global rise of civil society. It is scattered and needs knitting together. More and more young people under 30 want to be volunteers. At this conference, we have heard of an initiative in India by Dr. Solomon to network buddies in the developed world to fund medicines for children with AIDS and other diseases. On the 9th of October the UNDP together with Cisco Systems will launch Netaid, connecting millions of people through rock concerts and on the Net to match donors with projects. In France, Jacques Attali has devised a network to provide grass roots organizations all over Africa with income-generating projects. What is coalescing to alleviate poverty must give priority to care for children and focus on the orphans of the epidemic giving the best quality of care to those infected. There is not one type of model, but there must be a palette of models. Meanwhile, we must all lobby to prevent worldwide maternal infant transmission and set up health care structures; give medicine availability and help IAVI fund a cheap vaccine for the strains that affect 95% of those concerned. FXB is supporting the development of a cheap autogenously therapeutic vaccine developed by Dr. Jim Oleske.

What is needed is money and ways to channel it directly to trustworthy recipients supported by community based organizations and grassroots committed leaders. On a planet where the 3 richest people in the world own assets that exceed the combined GDP of the planet's poorest 48 countries, according to Jeff Sachs of the Center for International Development (CID) at Harvard.

The following may sound like a provocative dream and an unrealistic one, but many of the new relationships that we see budding today, and just mentioned, like the South African initiative between haves and have-nots seemed totally provocative and unrealistic 10 years ago.

So, what if the world's richest people compiled by Forbes magazine – almost 500 people worth more than 2 trillion dollars – gave 2% of their added wealth to children the orphans affected and infected by AIDS . That sum would make an endowment of \$40 billion, invested at 5% a year, as we do at FXB, it would yield \$2 billion annually for efforts to implement Article 24 of the Convention on the Rights of the Child. \$2 billion could provide the FXB Ugandan type program just mentioned for the 40 million orphans of 2010.

What about corporations which are not signatories to the UN Convention and are not accountable for respecting these rights? They must also be made to pay their dues to these children.

The demand must be put to these people and corporations. If they fail to respond, we will remind them of what Martin Luther King, Jr. said that in this generation “we will have to repent not so much for the evil deeds of wicked people, but for the appalling silence of good people.”

Forgotten issues of forgotten people in forgotten places have to be pushed forward with the support of the media. At this juncture of our history, sharing has become mandatory and unavoidable. AIDS is the single greatest threat to global development and economic sustainability for both the rich and poor.

Using the web and its technology to bypass bureaucracy and corruption, involving the international accounting companies and international volunteer lawyers, the Association Francois-Xavier Bagnoud and myself will undertake a realistic plan in the coming year to challenge and mobilize The Forbes 500 richest people and corporations to give 2% of the wealth to programs to provide basic human rights to children with priority to these AIDS orphans.

Thank you for letting me speak about the orphans who so urgently need our solidarity and help. Orphans that we must not allow the rich parts of the world to forget.

“We are one world, and these children are our children,” said Archbishop Desmond Tutu. “Their destiny is our destiny. Each one of us can make a difference. Each can help save lives.”