SPEECH

FXB international
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Strategies for expanding the international response to the AIDS orphans crisis: an action-oriented workshop

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If you factor in all of the affected children - the street kids in the world's mega cities as well as those affected by the ravages of AIDS, to the official orphan numbers, there will be as many as 200 million children at risk on all continents in the next decade. Because the 40 million in 23 countries in Africa are the showcase of what will inevitably surface in India and Asia, China, Russia, Colombia and other countries. Yes, this is a far larger estimate than the ones usually used and it is scary, if not numbing. But we can't deny the evidence of recurrent and inevitable patterns.

RELEVANT HIV/AIDS STATISTICS IN AFRICA

- Worldwide 1.3 million children under 15 years of age are currently living with HIV/AIDS.
- Nearly 4 million children under 15 years have died of AIDS since the beginning of the pandemic.
- More than 13 million children worldwide are single or double orphans and 90% of them live in Sub Saharan Africa (SSA).
- 80% of HIV infected women worldwide reside in Africa.
- SSA has 70% of the world's HIV infected children.
- 80% of HIV/AIDS deaths in children worldwide have occurred in SSA.
- In some countries of Africa up to 10% of the children <15 years are now orphans.
- Mortality rate of children less than 5 years in SSA is 173 per 1.000 live births[1] compared to the industrialized countries average of 6 per 1.000 live births. In 1960 the child mortality rate (under 5 years) in industrialized countries was 37 per 1000 live births.
- The overall childhood mortality rate in Africa is 300/1000 live births[2].
- Seroprevalence rates of HIV among pregnant women in SSA range form 5 to 35% with the highest rates reported in the urban centers of Kampala (Uganda), Lusaka (Zambia), Blantyre (Malawi), Kinshasa (Zaire), and Abidjan (Ivory Coast).
- A prominently high prevalence rate in excess of 80% has been reported for female sex workers in Central Africa[3].
- The published HIV prevalence rates in some SSA countries are Zambia (19%), Malawi (15%), Mozambique (14%), Rwanda (13%) and Kenya (12%).
- In several Southern African countries, namely South Africa, Zimbabwe, Botswana and Namibia, the prevalence rates of HIV infection in the adult populations currently exceed 20%.
- Some countries like South Africa have witnessed a three-fold increase in the HIV prevalence rates within two years (i.e. from 2.4% in 1992 to 7.5% in 1994).

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[1] Massawe Agustin; Dept. of Pediatrics, Muhimbili University College of Health Sciences, Dar es Salaam, Tanzania. Presented at the Research for HIV/AIDS Care, NIH Consultation in Gaborone, Botswana, March 25-29/2001.

[2] Musoke Philippa; Dept. of Pediatric, Makerere University. Kampala, Uganda.

[3] HIV/AIDS in Africa. Washington DC: US Bureau of Census.

The impact of HIV/AIDS on children surpasses the figures amply. The dynamic of the pandemic, as well as the social and economical impact on the communities, has practically turned to a negative number the population and economical growth rates in some of the affected countries.

Let me give a recent example out of 12 years experience in AFXB's field work:

RWANDA'S ORPHANS' "TIP OF THE ICEBERG"

The global dynamic of the HIV/AIDS epidemic can be translated into practice by analyzing, at the level of a small cohort of families directly affected by the virus.
Let's examine this tendency within a cohort of AFXB beneficiaries in Kigali, Rwanda beginning 2001.

- Nature of the project: Income Generating Activities (IGA) for families in which at least the head is living with HIV/AIDS, Medical and School support for their children and individual and group counseling.
- Total of households 240 of which the head of the family is: in 219 a widow, in 15 an Orphan and only in 6 both parents are alive.
- Total of persons benefited from the project: 1440
- Total number of children (<15 years) 907 of whom 73 (8%) are already double orphans.
- The average of children in care of each head of house is 4.

At present approximately 40% of the heads are Symptomatic (having an AIDS related condition), which means that they will survive a maximum of 1 to 2 years. Therefore approximately 360 children will loose their parent within the next 1 or 2 years.

Considering the natural history of the HIV infection and the maturity of the epidemic in Rwanda, we calculate that at least 80% of the heads of family of this cohort, will die within the next 4 years, living behind no less than 700 children.

Being these only the **"tip of the iceberg"**, and projecting the drift to the general population of Rwanda, the proportions turn unimaginable, specially within the current HIV infected women left behind with children, by their male couples who have died of AIDS. This is also supported by the fact that 19% of pregnant women tested within sero-surveillance sites in urban settings have been found HIV positive. Without systematic and widespread mother to child transmission (MTCT) prevention programs in place (this is the current situation[4]), approximately 50% of the children born to these mothers will be infected with HIV; however almost 100% will surely be orphans before they reach the age of 15 years, unless their mother's HIV infection is timely and effectively intervened (i.e. HAART).

Furthermore, access to, as well as acceptance of Voluntary Counseling and Testing (VCT) within some communities is far from the ideal, practically abolishing any possibility of cutting down the transmission rates. In some local communities[5] the majority of the population (4 out of 5) would not go for testing, due to:

1. Fear to know that they "have AIDS"
2. Fear to be stigmatized or rejected within their communities
3. Or simply because they believe that "there is nothing that can be done for this disease and knowing they are infected would not make a change"

[4] According to Etienne Karita, Director of the National Program of Fight Against AIDS (NPFAA) in Kigali, Rwanda in Apr. 1999 pilot MTCT interventions where initiated, but are not yet widely spread with in the country. Personal communication April, 2001.

[5] Personal communication with the AFXB Kigali and Gitarama Staff. Apr. 2001

In addition, the use of condoms by the sexually active population in Rwanda is very low (officially reported 9% by the NPFAA in 1997). In some local dispensaries the Family Planning programs have 0% of condom use[6].

Here is another example, showing the development of HIV/AIDS in war affected areas.

VIOLENCE AND HIV: A CASE OF A DOUBLE VICTIM FROM KIGALI

This is a somewhat common case in Rwanda, of a women living with HIV/AIDS who lost her entire family during the genocide, adopted an orphan child and is currently struggling and with full-blown AIDS.

Caritas Mukandoli is a 48-year-old woman, living in Bilyogo, one of the poorest and overpopulated sectors of Kigali. Her husband died of AIDS in 1987; she then decided to be tested for HIV, finding herself positive. Her four children were killed during the 1994 genocide. *Caritas* adopted *Jeanne*, a female orphan who also lost her parents during the genocide and is currently 14 years old.

In July 2000 she was part of the first group of AFXB beneficiaries who received an IGA (selling fruits and vegetables), allowing her to make a small income which helped improve her and Jeanne's quality of life. Unfortunately since January her health condition worsened, sending her to the hospital for two times within the last 3 months. Consequently, she used all the IGA money in order to pay her health expenditures and therefore the IGA was lost. Caritas has lost hope; her health condition is not responding to the basic treatment that she is prescribed at the local dispensary and therefore is often depressed and aggressive to those who surround her, including the AFXB team. Jeanne, who was attending the first year of secondary school, had no other choice than quitting her education, in order to take care of her sick mother and thus, putting at risk her own future.

Carita's case is one perfect example of the persistent destruction that the HIV is carrying out within the most destitute of all. The future of many Jeannes is obscure and many Caritas will die, unless we stop the trend of the epidemic. Prevention efforts have been generally weak, and were strong, have failed to effectively control the epidemic. The health infrastructure is constrained by the high demand that Opportunistic Infections and HIV/AIDS associated illnesses. Yet, antiretrovirals, proven to be effective in stopping and even reversing the destruction of the immune system (at last responsible for Carita's current health status) even if currently available at an average of one dollar per day per person, will not reach the many Caritas today in need.

If parent's health is preserved, we will have fewer orphans in the future.

What are the practical challenges faced by AIDS orphans and their communities?

Facing death - emotionally

We all know that AIDS affects children long before their parents die, and there are a number of factors that contribute to these facts. While parents are sick or dying of HIV/AIDS at home, the entire family is concentrated on the person who is sick. The child is unintentionally neglected. It is heartbreaking for kids to see their role model (parents) sick and no longer active as before, or unable to do things for themselves or their children.

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[6] Med Assistant Augustin at the Umushumba Mwiza Health dispensary in Muhima sector, Kigali. Personal communication. Apr. 2001.

In most cases, adults shun children from taking care of their parents and loved ones. The stigma associated with disclosing an HIV diagnosis remains prevalent and results in many ill and dying parents choosing not to disclose to their caregivers, families or children.

This often results in “silence” about their children’s future. In stark contrast, parents and mothers in particular, who are confronting their imminent death, universally express concern about who will care for their kids. Emotionally these children are not being attended to.

Education
In some African countries, AIDS affect so many teachers that schools have to be closed down. Furthermore, AIDS orphans living in the streets do not have the financial resources to afford school fees, books and uniforms. They will not only be unequipped to become productive citizens but in order to survive these uneducated, decivilized children will return to "barbary".

Health care
Since most of the countries where AIDS orphans live can not afford proper health care systems, health care facilities are almost always non-existent for orphans. They can not afford basic medication or treatments. Overall, hygiene conditions are very poor.

Economic opportunities
As in most countries where the number of AIDS orphans is rapidly growing, adults are already facing unemployment. It is clear that economics opportunities are virtually non-existing for AIDS orphans. They might become a permanent class of unemployed and unemployable people. Will they join armies as child soldiers? Terrorist groups? Fall into barbarism after falling out of a fragile social safety net? Will they fuel more disruption and dislocation in many countries that will never develop to their potential?

Children do not vote, nor lobby. They don't buy, and when orphaned cannot pressure parents to do so. Orphans are no market incentive so they are ignored by the affluent and powerful world. It is our challenge to make their voices heard!

How, where and by whom have the practical challenges been effectively addressed?

Integrated approach. Some NGOs have been able to address these practical challenges. At AFXB, we use an integrated approach that involves local communities and deals with income generating activities, school support (tuition, books, uniforms, lunches), basic health coverage, psychosocial assistance, AIDS prevention and testing and, where it’s possible, access to antiretroviral treatments.

Community based. We do not believe in putting orphans in institutions. We use a community based solution. In most cases guardians who take in orphans, are not really in a position to do so, due to the fact that they themselves are unemployed. Taking in another child to feed, clothe and educate is a huge financial burden. We provide such guardians with income generating activities (IGA) to enable these children to remain in their communities, where they will be loved, protected and taken care of. We further get involved with providing school support, basic health coverage and the other activities described before.

In India, **for example**, FXB has been actively investigating and implementing means to change behaviors and curb the spread of HIV infection. Over a 3-year period, over 10 800 individuals will be trained in over 180 villages. Some of our most important goals are to assist the country in controlling HIV transmission and to prevent its further spread - especially in rural areas. One goal is to provide home-based care to people suffering from HIV/AIDS, including children. We provide orphan support programs and are committed to working for the integration of orphans into their communities.

A few AFXB statistics worldwide

Beneficiaries	Direct	Indirect
AFXB school support	10’000	50’000
AFXB basic health assistance	10’000	
AFXB income generating activities	15’000	75’000
AFXB after school projects	1’000	3’000
AFXB HIV/AIDS testing	75’000	1’000’000
AFXB HIV/AIDS prevention programs	88'000	1'088’000

In many parts of South Africa, many of the families and guardians who care for the orphans cannot afford to prepare daily meals for the children in their care. In addition, the children have to travel many miles to go to a school where the fees are less expensive. AFXB is providing the school with a kitchen and will prepare meals for the children until the families can become self-sufficient through the provision of income-generating activities that AFXB is providing.

What are the key responses that can and should be scaled?

Proven effective treatment extended to all aids patients in poor countries.

- without treatment, 36 million people are going to die.
- without treatment the already terrifying figures of aids orphans will increase so much that the actual fabric of societies in many part of the world will be gone within few years.
- prevention without treatment doesn't work. With no hope for any treatment and the prevalence of stigmatization why should one get tested?
- global response on treatment is not found rapidly. In some African countries (Zambia) teachers are dying at such a rate that they can hardly be replaced by the newly trained.

How much do they cost?

- A $25 million fund for 3 to 5 years shall be put at the disposal of a small coalition of selected organizations and individuals in order to establish with scientific criteria the optimal protocols/regimens of treatment in a selected number of poor countries. This would establish a proven effective module that could be replicated after 3 to 5 years on a much larger scale. The regional level shall be the target. Indispensable will be the participation of local Ma with large field experience in the treatment of HIV / AIDS patients, epidemiologists, researchers from academic institutes and medical schools, government agencies, health worker networks and ceo1s.
- A multibillion (3 to 5) fund shall be established in order to train the various actors at national and regional levels to use and multiply the set module.

What constraints exist?

The existing structures and their traditional “modus operandi “ Too heavy, too lengthy, too complex with scattered and diffuse responsibilities, hyper stable systems where the objectives get lost, corruption.

The perverted image given by major actors for so long about this hopeless, deadlocked question of treating the poor in the South:

- lack of trained staff, meaning well trained in the North.
- lack of infrastructures. meaning heavy, sophisticated, expensive equipment from the North
- much too complex and risky to be tried in poor settings.
- too expensive
- and so on....

- the fact that major donors understood the magnitude of the problem and are reluctant to spread monies to a growing number of projects without any hope of reaching ever a global solution/impact.

How can the constraints be overcome?

- Cutting edge responses, impact oriented approaches, no prejudice.
- Using the best means and tools within the existing system without being trapped in it.
- Setting up less heavy, formal procedures, being more flexible.
- Use new models like the campaign against landmines.
- Conceive a carefully and well thought strategic plan with few major players from this field backed and supported by networks of key players chosen for their skills, competences and their personal commitment before their link to an organization.

> The AIDS orphans crisis has affected the elderly who now have to care for their orphaned grandchildren. In Thailand, academics and a community organization set up the Grandma Project that brings together 30 grandparents to meet once a month to discuss their needs and concerns. There are 300 grandparents participating in the project.
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> They are given information about how to take care of members with HIV, their grandchildren's health and well being, in addition to keeping fit themselves. They are also advised about their rights to free state medical care and social welfare benefits. Projects like this however are few and far between. They can only support a fraction of those grandparents who have been affected, including providing financial assistance toward the grandchildren's education.

What should the international community do to support these responses? What agencies and institutions can be involved, and what roles can they play?

A major effort in learning about the reality of the situation. Keeping hope because mankind has proven incredibly resourceful, imaginative, courageous and capable. Governments, the UN, UN agencies like UNAIDS, WHO, UNICEF, WB, EEC, regional organizations, NGO's, CBO's, funding agencies, private foundations. They shall play their traditional role but due to the emergency of this situation they shall designate according to the criteria mentioned above one key official with a large margin of maneuver to become part of the hardcore network which is essential to the success.

On the local level it will be crucial to involve whatever public and private resources in the campaign.

What is needed to galvanize international action on the AIDS orphan crisis? (advocacy, policy advice, partnerships, etc.)

DATA BASE
PUBLIC INTERVENTIONS
SPEACHES IN GOVNMTS…
INTERNET
PETITION

AIDS is a global challenge, because in this age of globalization, we are already one big village, with common and shared problems, and where any dysfunctional neighborhood in the village impacts the rich one next door.

Perhaps we need to start thinking of AIDS itself, as some scholars like England's Tony Barnett are, as the first plague of the era of globalization! Everyone needs to be involved: individuals, organization, groups, governments, etc. and this at every level.

The rescuing of the growing numbers of orphans of village Earth is everyone's problem. In order to galvanize international action, we need to get this message across.

The children who are left when parents die only add another complex dimension to Africa's epidemic. At 17, Tsepho Phale has been head of an indigent household of three young boys in the dusty township of Monarch, outside Francistown, for two years. He never met his father, his mother died of AIDS, and the grieving children possess only a raw concrete shell of a house. The boys sleep on piled-up blankets, their few clothes dangling from nails. In the room that passes for a kitchen, two paraffin burners sit on the dirt floor alongside the month's food: four cabbages, a bag of oranges and one of potatoes, three sacks of flour, some yeast, two jars of oil and two cartons of milk. Next to a dirty stack of plastic pans lies the mealy meal and rice that will provide their main sustenance for the month. A couple of bars of soap and two rolls of toilet paper also have to last the month. Tsepho has just brought these rations home from the social-service center where the "orphan grants" are doled out. Tsepho has been robbed of a childhood that was grim before his mother fell sick. She supported the family by "buying and selling things," he says, but she never earned more than a pittance. When his middle brother was knocked down by a car and left physically and mentally disabled, Tsepho's mother used the insurance money to build this house, so she would have one thing of value to leave her children.

As the walls went up, she fell sick. Tsepho had to nurse her, bathe her, attend to her bodily functions, and try to feed her. Her one fear as she lay dying was that her rural relatives would try to steal the house. She wrote a letter bequeathing it to her sons and bade Tsepho has to hide it.