SPEECH

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Global Challenges for Children Affected by HIV/AIDS

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HIV/AIDS has been a major cause of mortality around the world. To date, most deaths, and most people currently living with HIV/AIDS, are found in sub-Saharan Africa, but the pandemic is quickly spreading around the world. It is not just the afflicted who suffer; the pandemic devastates communities, whole countries, and their economies. It also leaves in its wake vast number of orphans and the numbers are daunting.

In 1999 UNAIDS estimates projected that, in the worst affected 23 countries of Africa there would be 40 million children orphaned by AIDS in 2010. This figure was later reduced to 25 million children. So it is based on this last figure, that at AFXB we are working with the assumption that the total number of orphans and vulnerable children affected by the pandemic will probably exceed 100 million children by the end of this decade. The rationale for this is that many more children than those who can accurately be defined as orphans will also be affected: either those who experience the same impact from the pandemic as orphans ('de facto orphans'), or children not orphaned themselves but indirectly impacted and if we had based ourselves on the first UNAIDS estimate, which was probably the right one, we would find around 160 million as the total number of Orphans and vulnerable children affected by the pandemic at the end of the decade.

By 'de facto' orphans, we include those children whose parent's capability to care for them is diminished because they are living with HIV/AIDS. The second category of non-orphans who are indirectly impacted includes children whose families have fostered orphans; consequently having negative impacts on household economy, food security, etc and leaving their children without access to their basic rights as specified in the 44 articles of CRC and ratified by all countries except the USA.

Our inclusion of orphans and vulnerable children of the HIV/AIDS pandemic can be outlined as follows.

All children who have lost either one or both parents. These may be paternal orphans, those whose father has died; maternal orphans, those whose mother has died; or double orphans, children who have lost both parents.

We stress the need to include paternal orphans, as they have been excluded from many accounts, and yet our own research has demonstrated many to be among the most vulnerable of all orphans. We do not regard the definition of 'AIDS orphan', meaning children whose parents have died of AIDS, as sufficient for planning programmatic responses to the crisis. Many more children are affected by the pandemic, because they live in HIV/AIDS impacted communities, which reduce coping capacity for their care. Also it is often impossible to know the actual cause of death of each parent, especially when the cause is as stigmatizing as HIV/AIDS.

We also include all children up to 18 years of age, in line with the UN Convention of the Rights of the Child, rather than using a cut off age of 15, as is still used for UNAIDS data.

This is especially important in the case or orphans, s our own research has demonstrated that orphanhood can delay the development of children.

Children who lack parental care experience the same needs as children with deceased parents. Many 'non-orphans' are perhaps better described as 'de facto orphans'. Where there is high HIV positive prevalence we can expect to find many surviving parents debilitated by symptomatic HIV and AIDS. Naturally, some of their children, especially the younger ones, may be living with HIV/AIDS themselves. The children will have to cope with the distress of caring for their parents through long terminal illnesses. The household is likely to be experiencing a devastating economic impact at this stage. There is no doubt that many orphans will be in stronger position to cope had they received support at this stage, rather than after orphanhood has occurred.

De facto double orphanhood can also apply to children who are normally defined as just orphans, in that single orphans can also be de facto double orphans. When HIV/AIDS is the cause of orphaning, the surviving parent may be too ill to take full care of the children. Sometimes paternal orphans are separated from their mothers due to the economic hardship of widowhood, or because of cultural practices that decree that paternal orphans should be fostered by a paternal uncle to maintain patrilineal inheritance.

'Street children' should also be included as de facto orphans, where they are living without parental care. HIV/AIDS in the family as a cause of children living in the streets is a synergy that has not been thoroughly researched. However, in our research in India, street children have cited their mother's widowhood as the reason for leaving home. What is known is that children living on city streets and railway platforms are at extreme risk from HIV themselves.

Another number that we have to remember is that according to USAIDS in 1991, there were already 100 million children living on the streets of our mega-cities before HIV/AIDS generated millions of orphans and today there are 75 million orphaned children in the world of other causes. That is why FXB and I are doing "back of the envelope" calculations on those populations of children that are not included in our FXB's scientific studies of 100 million AIDS Orphans and vulnerable children at the end of the decade in HIV/AIDS impacted settings. We say that the world population of AIDS Orphans, orphans and vulnerable children of all causes will be closer to 200 million.

The suffering of AIDS orphans and their lack of access to basic services such as education and health is the showcase of the huge population of desocialized children that our Global Village will have to cope with in the next decade.

Without assistance, many AIDS orphans will drop from school; will be pushed into abusive child labor, including sex work. They may well end up living on the streets, or become as in Africa, child soldiers. They may become prey to the same virus that took their parents because orphanhood places them in a vulnerable position. The stories of children who have to survive by any means and the consequent desocialization that they fall into are mind-boggling. The barbarity, which they are pushed into and will therefore grow up into, is horrific in terms of ethics, security and the cohesiveness of the global family.

A West African commander once said that a twelve year old is the ideal soldier, old enough to carry a gun and execute orders but too young to have any compunctions about acts of barbaric human destruction.

It takes resources to carry out solutions for this crisis but resources mobilized at this juncture are a long way short of what is required. Children do not vote, they do not have the power to lobby governments. They do not buy, and orphans no longer have parents to represent them as consumers and give them political importance.

The economic impact of an orphan crisis on the rest of the world is not obvious, and yet if we allow so many young people to be deprived and excluded from opportunity we are clearly diminishing the world's greatest resource for the future – our children, the next generation. And the AIDS orphaning segment of left out children is growing every minute that goes by.

As HIV/AIDS has orphaned millions of children, and threatens to orphan many millions more, in other countries than those where they are counted today, then the vast numbers of orphans involved here places HIV/AIDS in need of special consideration in terms of the overall situation of orphans worldwide.

However, there are many other factors that mean that we must give special consideration to those orphaned by the pandemic.

One of the most devastating impacts of the HIV/AIDS pandemic has been that most of the victims are in the 15-50 age group. This not only means that large numbers of parents are dying, causing a large numbers of orphans but that many of the potential care-givers to these orphans are also dying or falling ill.

As numbers of orphans increase and the number of people to take care of them is decreasing. In areas of the world, such as sub-Saharan Africa, that already experience a "mature crisis" of HIV/AIDS, we see households having to take care of large number of orphans, and we see elderly relatives, most of them in need of care themselves, having to take on the responsibility of their children's children, at the same time as losing the support of the most productive generation.

If it is known that a child's parent has died from AIDS, any stigma that exist in the local community in relation to HIV/AIDS is likely to become attached to the child. This will add to the psychological trauma of becoming orphaned.

These attitudes may also affect the child's access to care, for example:

- There may be a fear that the child is infectious
- Potential foster families may fear that stigma will enter their household if an AIDS orphan is fostered into it
- The child may carry the parent's 'shame' of 'sexual disease'

HIV/AIDS usually causes a lengthy period of illness that requires care and support from the family. The children will have to act as caregivers to their parents through a long and terrible illness. The suffering of a parent may begin traumatizing a child before she is actually orphaned.

This also means that the poverty impact of the illness (e.g. loss of labor and income + cost of care) takes effect before orphaning occurs.

A further impact is that the sexually transmitted nature of HIV means that as one parent becomes infected, so it is very likely the other will too. In some cases children may have to take care of both parents themselves. In other cases the children will have to find alternate caregivers, or be sent away to institutional care, while their parents are still alive. For others, the period of caring for a sick parent may become protracted even further; as they attend the funeral of one parent, while the other is beginning to succumb to the virus.

In India, it is difficult to discuss any aspect of the HIV/AIDS impact without bringing up the subject of labor migration. Migrant laborers are one of the highest HIV risk groups in India, especially among the married population, thus labor migration has a major impact on orphaning in this country.

One consequence of this is that orphaning is likely to occur in the location of the migrant workers families (often rural villages), rather than close to the source of infection of the migrant fathers' place of residence. Therefore we cannot assume that the highest frequency of orphaning will occur where AIDS mortality is recorded to be most prevalent.

Also, labor migration is most common where this is a common strategy to relieve poverty. Consequently, as orphaning causes poverty there is a tendency for orphanhood to lead to migrant work, often undertaken by orphan boys.

When the mother dies, typically it is her children who will have to take over her roles in the household. This constraint is especially high for girls. Infants are often cared for by siblings rather than a true mother. Children, especially girls become less likely to attend school and are denied a proper childhood.

When the father dies, the main material problem is the loss of the 'breadwinner'. Poverty is thus increased among poor households, better off families are likely to be pushed into poverty. The mother and/or the children have to take over this role. Where the mother is able to find work, usually for less pay than her husband, the household is pushed into the same pattern as for maternal orphans. Alternatively, pressure for child labor is placed upon the family.

Many widows have inherited debts from their husbands, and often resort to further borrowing from unscrupulous lenders in order to care for their children. Again this increases pressure for child labor migration and sex work. Many sex workers interviewed in Goa were found to be widows, in some cases with their daughters following their trade.

Orphans who are not given support in their communities are likely to fall into institutional care. There are many problems associated with institutional care, or orphanages, and this is being increasingly seen as an inadequate response to the increasing numbers of orphans from HIV/AIDS.

Firstly, this is too expensive; it would take billions of dollars every year to take care of the world's AIDS orphans in orphanages.

Secondly, institutional care is not the right environment for child development. Children should grow up in a family environment that is conducive to their own culture and be loved. Experience from Africa, where HIV/AIDS has had the biggest impact so far, shows that orphans can be kept in a family environment, in spite of the challenges involved, as long as adequate support is given. Experience shows that adequate support can be provided through community based projects at as fraction of the cost of institutional care.

And, this has a side benefit of developing sustainable of economic activities that are also part of a network of projects for poverty alleviation and ultimately eradication.

So the challenges faced are enormous.

To provide care and support to 100 million orphaned children may seem to be a daunting task. However, if successful programs are replicated across the globe then this can be achieved. In Uganda, they have a saying "to eat a whole elephant is easy, you just cut it into small portions". Small-scale programs have been shown to work, we simply need more of them to achieve our mammoth task.

The true numbers of children affected by the AIDS orphan crisis of the Global Village are incalculable, but very likely exceed 100 million by the end of this decade, unless action is put in place to reduce numbers of orphans by reducing HIV positive-prevalence, and to reduce the indirect impacts through interventions that support orphan caring households.

The stigma of HIV/AIDS becomes a great problem for the orphans of the pandemic, who may carry the label of AIDS with them. It is important that projects in support of orphaned children do not focus purely on "AIDS orphans", as this is bound to label all children supported by the project with the stigma of the pandemic.

School drop outs, or children unable to even start school, especially girls, are very likely to result from orphaning. Programs aimed at increasing literacy can be undermined by large-scale orphaning and by the death of teachers. In Malawi 7 teachers are trained because only one will make it to the classroom!

There will be a burden placed on the elderly, as they have to care for their grandchildren. This also places some doubt as to who really is the caregiver in such households. Are the grandparents caring for orphaned grandchildren, or the children acting as caregivers to the elderly?

Children may be sent to live in orphanages. This is never the most cost effective intervention for orphan care. Orphanages are often poorly run, and are likely to become increasingly overburdened as orphan numbers increase. Life in an orphanage nearly always leads to institutionalization of the child, and is never the best environment for child development.

A large number of orphaned children in India are left homeless, adding to the numbers of 'street kids' and 'platform kids'. This may be because they are double orphaned and have nowhere else to go, or because the loss of one parent has placed pressure on the household and forced them away. Some of these children have left home in search of work, because of the pressure for child labor. Girls are usually recruited into sex work as soon as they arrive at a major rail station.

The global problem of desocialized children goes beyond the AIDS orphan crisis, but for all homeless children the threat of HIV/AIDS is looming.

In addition to the hardship endured by homeless children, there is also a terrible irony about their plights: orphanhood, which is likely to be caused by HIV/AIDS, becomes a factor that increases a child's risk of HIV/AIDS infection.

An insight into the lives of children orphaned by the pandemic presents a bleak and a heartbreaking picture. But, it does not have to be this way. FXB has programs that go a long way to alleviating the pressures or orphanhood implemented in many African communities. If these programs are focused on the local community, then local capacity to provide care is reinforced, reducing further the impact of orphaning on communities already impacted by the plague of HIV/AIDS. We consider our programs instead of being of "assistance" to be an investment into the sustainable future of the community.

Over the past 14 years, AFXB has already developed a proven track record for initiating programs that work, providing high levels of care and support both to orphans and their caregivers in HIV/AIDS impacted communities. Our programs adopt a community-based approach, a strategy that is widely accepted as a 'best practice' policy by all lending researchers and theoreticians in the field, but still widely ignored by many practitioners. An example of this is the AFXB Uganda Program, which has assisted more than 3,300 orphaned children and their families (1,600 households).

The program has set up village orphan committees (VOCs) made up of local community members and rescue the orphans' families with income generating activities to alleviate the constraints of orphanhood. This approach involves and enables the local community in providing care and support to their orphans. Throughout Africa, tradition dictates that vulnerable children should always be provided for, but the HIV/AIDS pandemic has undermined many communities' capability to do this. AFXB programs do not focus solely on the target group but set out to solve the core problems at their roots. The AFXB Uganda program was recognized at the XIVth International AIDS Conference in Barcelona, Spain in July 2002 as an outstanding approach.

AFXB's activities have also demonstrated a certain amount of versatility, an essential attribute when dealing with a crisis as diverse and varied as the impact of HIV/AIDS. In addition to programs specifically aimed at orphaned children, we also have projects that work with street children and the children of sex workers, both related issues to orphans programs. In India, there are projects targeting the health issues of migrant workers and their families, some of the most vulnerable households to the pandemic. There are also projects involved with other issues of HIV/AIDS, for example, care and support interventions for people living with HIV/AIDS in resource poor locations. Such an intervention provides a strong linkage with orphan care programs, as it enables children affected by HIV/AIDS to be identified before they become orphans. There are also many AFXB activities that promote greater knowledge of HI/AIDS to people often denied access to vital information.

AIDS orphaning presents an emergency. Children grow up fast and many do so in the worst imaginable conditions. And yet if successful programs are scaled up to a global response, the children of the pandemic need not be a lost generation, but can be display cutting edge response for the global crisis of de-socialized youth of other causes.

Nelson Mandela said there is no keener reflection of a society's soul than the way it treats its children. Let us hope that our Global Village will rise to the challenge and look back saying " we did for the children of Planet Earth what we had to do ".

Thank you (Nandri)