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A Challenge to Humanitarian Organizations
Born into the heart of a storm

Ndungu Kahihu

"We are angry. Our people are dying.
We can no longer accept millions of needless AIDS deaths
simply because we are poor Africans" (Milly Katana, Uganda).[1]

The AIDS disaster

Much has been written about the impact that HIV/AIDS has had on communities, on men, women and children. One of the facts that many people seem to agree on is that AIDS is an unprecedented humanitarian disaster, perhaps the greatest that the human race has faced in recent history. It is not a surprise, therefore, that the global response (if we ignore the early years of confusion) has tended to follow the typical humanitarian disaster response model. This model can be summarized in three basic steps, normally applied in linear progression from the start of a disaster to its resolution:

Arresting the immediate effect of the disaster on people

This is mainly accomplished by either moving people away from harm or removing the causes of harm. In man-made or natural disasters this includes evacuation and protection, provision of emergency shelter and care, creating safe spaces and providing clean water, food and other basic necessities required to keep people alive. The global effort to provide antiretroviral drugs (ARVs) to people infected by HIV can be seen as such a first line response to the AIDS disaster. Before the development of ARVs, this response was confined mainly to public education campaigns and other programs designed to keep people from falling into harm, by becoming infected or by spreading infection.

[1] As quoted in: "Stepping back from the edge: The pursuit of antiretroviral therapy in Botswana, South Africa and Uganda." (UNAIDS 2003)

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Helping people to rebuild their lives and return to normalcy

This includes work to reconstruct shelters, schools, hospitals and other facilities that may have been destroyed by the disaster. This has a practical as well as a symbolic value, which is to bring back a sense of normalcy by recreating, as much as possible, the reality that described people's lives prior to the disaster. It is an important step in helping to move affected people away from the state of being victims to survivors. Some of the most challenging HIV/AIDS response initiatives today are at this stage. Programs that address the problem of stigma by encouraging communities to view those affected by AIDS as 'normal' people, deserving of acceptance rather than rejection, fall into this category. So do programs designed to help individuals accept the prospect of imminent death and plan for it; the creation of legal systems that protect the rights of HIV/AIDS affected people; strengthening of family systems to enable them to provide care for orphans etc. The idea is to create a world that accepts AIDS as a manageable reality of life, rather than waiting for science to produce a magic fix that will somehow make it disappear.

Addressing the root causes of the disaster and planning how to survive future ones

Also sometimes known as the 'never again phase,' this involves examining the causes that brought about the disaster in the first place and whether it could have been avoided. Secondly it involves analyzing the impact that the disaster has had on the people, why they were vulnerable to it and if such vulnerability can be reduced, thus mitigating the potential impact of similar disasters in future. Finally this phase involves making sometimes difficult decisions and hard choices in order to help people avoid future disasters, if they can, or at least escape the greatest harm from them. Such choices might involve moving away from disaster- prone areas, changing a people's way of life or learning a new set of coping skills.

For HIV/AIDS, this phase has involved asking such questions as: Why has the pandemic had such a disproportionate impact on sub-Saharan Africa? What could have been done, but was not done, to arrest the spread of infection and the deaths of millions that followed? If a similar disaster struck tomorrow how prepared are we for it? While debate around these and similar questions is still going on, several lessons can already been drawn from the disaster experience so far:

- First, the socio-economic conditions that prevail in much of sub-Saharan Africa, characterized by increasing poverty, disease and malnutrition, have contributed to turning AIDS from a survivable crisis into a humanitarian disaster. It is not a coincidence that the greatest impact of HIV/AIDS—the numbers of the dead, the infection rates and the greatest socio-economic impact—is closely correlated with patterns of poor governance, poverty and economic decline. There is evidence that the global community is finally starting to address these problems with the seriousness they deserve, as seen from the recent international forums at which concrete plans to lower trade barriers, eliminate debt and increase development assistance to poor countries have been proposed.

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- Secondly, HIV/AIDS is primarily a behaviour-driven disaster; it follows, therefore, that people's behaviour has to change for its impact to be mitigated and overcome altogether. This is already happening, albeit slowly, partly as a result of the behaviour change and communication campaigns of the last 10 years, but also because as people come to terms with the disaster, they realize they have the power to overcome it if they act together and believe in themselves.

- Finally and most importantly, the future for Africa lies in ensuring that the members of the young generation are protected, given the skills to avoid infection or infecting others and otherwise supported to live positive lives so that they in turn can help bring about an AIDS-free tomorrow for Africa.

  Unfortunately this is where our application of the disaster response typology falls down; where promised actions have not followed words spoken. One would expect that, in a continent where half of all inhabitants are children, a proportionate amount of resources would be allocated to addressing the impact that HIV/AIDS has on them. This is not the case. In fact it seems that the impact that HIV/AIDS has on children has not been understood well, which may explain the failure of many of us to act on their behalf.[2] What is the nature of this impact?

Impact of AIDS on children

If you are a child growing up in most countries of sub-Saharan Africa today, it is almost inevitable that, by the time you exit childhood, your life will have been negatively affected by the HIV/AIDS pandemic[3]. Here are just a few of the ways that this is likely to happen:

You will be born HIV positive or become infected when still a child

Mother to child transmission is the second most common way that HIV/AIDS is passed on in Africa. UNICEF estimates that 2.1 million children live with the HIV virus and more than 90 per cent of them contracted it at the point of birth[4]. This number would be much higher were it not for the fact that many of these children do not live to see their second birthday. While the majority succumb to the ravages of immuno-suppression and the opportunistic infections that follow, an increasing number are now dying because they have been abandoned.

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[2] Strange in that in many other social development areas—education, environment, health etc—the place of children and the need to address the different ways they are affected have been clearly identified and often followed by a commitment of resources to address these issues.
[3] We define children according to the UN definition contained in the International Convention on the Rights of the Child (ICRC), as any person who is under 18 years of age.
[4] Children on the Brink 2004 (UNICEF)

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Many children also become infected through adolescent sexual activity. In fact more than half of all new infections in Africa are now occurring among children below the age of 15. Girls face a disproportionate risk of infection, with the ratio of girls infected to boys being 5:1. The conditions of poverty and deprivation, which normally accompany HIV/AIDS prevalence, put pressure on children to engage in risky sexual behaviour in order to survive. Increases in the incidence of child sexual exploitation, which further fuels the spread of infection, have been observed in every African country where AIDS is highly prevalent.

You will lose one or both your parents to HIV/AIDS

One out of every 10 children alive in Africa today is an orphan. Since 1990, more than 12 million children have become orphaned by AIDS alone, a number that is expected to more than double in the next 10 years[5]. This is by far the gravest impact that this pandemic is having on Africa today. While the death of children is a tragic thing to consider, the loss of parents in a social system that does not provide a welfare safety net and where the traditional care-giving family systems have collapsed, presents an equally terrible prospect, one not too far removed from death itself. UNICEF reports that over half of all orphans are forced to fend for themselves, drop out of school and become street urchins; in many cases, these are the lucky ones. Many others become victims of abuse, abandonment and early death. Those who survive start what becomes the beginning of a self-reinforcing intergenerational cycle in which the spectre of AIDS, like poverty in much of Africa, is inherited by children from their elders and passed on to their children in turn, with the prospect of breaking out of this vicious chain getting dimmer with each succeeding generation.

All societies that have aspired to make a better life for themselves have pointed to their children as the key reason for seeking such change and counted on them as the main instrument with which to sustain this transformation. This is no different for Africans, except that now millions of children are growing up without the role models that would normally project for them such visions of hope or nurture their innate aspirations to do better than their parents. How could such children aspire for a better life after watching, as many do, their parents come to an undignified, untimely death, often after years of protracted suffering?

Worse, the rest of the world seems to have arrived at the dangerous point where we see this situation as either normal or beyond redemption. This is reflected not only in our attitudes but in the language we use. We are now comfortable speaking of failed nations, a lost decade for Africa. How long before we speak of failed races, a failed continent, a failed generation? And how long before we seek to apply the principle of market capitalism to this slow onset humanitarian tragedy, one where only the strong need survive? The greatest danger, however, lies in the fact that many of the victims of this situation seem to accept their situation as normal too. Poverty, hunger and hopelessness have become the common coin of a majority of the current generation of adults in Africa,

[5] State of the World's Children, 2004 (UNICEF)

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one that has grown used to broken promises, to being failed time after time by the world and by their own. Tragically a new generation is coming of age that will inherit this mix, adding anger and bitterness to it and turning it into an explosive concoction that will bode no good for the human race. What will happen next is for us to decide and for history to record.

Your education will be disrupted

Your teacher will die or you will be forced to drop out of school to care for your siblings or a sick parent (especially if you are a girl) or because there is no one left to pay school fees for you. While children in the developed world take education for granted, the situation is not the same for Africa. AIDS has taken its biggest toll among the professional classes. Some countries have lost over 30 per cent of their teachers to AIDS. The death of parents further contributes to this problem. In Tanzania, for instance, studies have shown that the average school enrolment rate for children with both parents alive is 71 per cent. This number falls to 52 per cent when one or both parents die[6].

Significant gains have been made in Africa over the past three decades to reduce illiteracy by increasing school enrolment rates and especially to increase access to education for girls. Many of these gains are now being lost to the negative impact of AIDS. Millions of children are forced to drop out of school and again the disproportionate impact falls on girls. They are often the first to be withdrawn in order to take care of a sick parent or siblings, or when resources cannot go around and a choice has to be made whether to educate the son or the daughter. As a result, a new class of vulnerable children has emerged, namely, children who are heads of households. These are overwhelmingly girls, often forced to assume this role when a parent dies and there is no adult able or willing to take up the parenting role.

You will die of a cause related to AIDS

Seven out of every ten deaths of children can be attributed to a few preventable causes: acute respiratory infections (ARI), diarrhea, measles or malaria. In most cases malnutrition has been the most important complicating factor until HIV/AIDS came on the scene. The loss of immunity makes a child more susceptible to infection and makes it harder to recover from diseases, even where treatment is available. No wonder that, as of 2004, 3 million children were estimated to have died of causes that could be directly linked to HIV and AIDS[7].

The situation is worse when it comes to the availability of antiretroviral drug therapy for children. As a child living in Africa, you will possibly hear a lot of promises made by governments and other "big" people that they will provide so many of their citizens with life-giving antiretroviral drugs (ARVs). But you might as well plug your ears as none of

[6] Children on the Brink 2004 (UNICEF)
[7] "Beyond the Targets: Ensuring children benefit from expanded access to HIV/AIDS treatment." (Save the Children, 2004)

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these promises are really meant for you. The international community has made very little effort to provide ARVs for children. In fact more energy, it seems, is wasted in academic arguments about the morality, or lack of it, of doing so; or in futile hand-wringing at the big challenges of providing ARVs safely to children. The pharmaceutical companies that develop and produce these drugs do not prioritize children, with the consequence that, where they are available at all, pediatric ARVs are much more expensive than adult dosages.

To date many programs have been announced to provide ARVs to millions of adults around the world, with the WHO's 3 by 5 program being the most ambitious single program of this nature. At the same time the most extensive program to provide similar life-saving drugs to children was only announced in May 2005 by the Clinton foundation.[8] This program will work with a manufacturer of generic drugs in India and with several African governments to provide ARVs to 10,000 children. This is good, however, when you consider that there are more than a million children who could benefit from such drugs today, it is not enough.

AIDS: everybody's problem

The conditions which spread poverty, hunger and disease and thus make it so hard for Africans to survive AIDS could be alleviated if more of us were willing to share, if the world's nations were willing to make the sacrifices necessary in order to redress the economic playing field so that every society is given access to sufficient resources to guarantee a minimum standard of living for its members. None of the causes, including HIV/AIDS, that contribute to cutting short the lives of thousands of children and turning the living conditions of millions more into hell are inevitable. For instance, the case has been made many times that, for a fraction of the resources we apply to killing each other, humanity could guarantee life, health and education to every child on earth who needs it. The AIDS epidemic has helped magnify these facts in a most tragic and hard to ignore way. The power of a pervasive media ensures that the millions who are dying are no longer faceless others from a faraway place but intimate members of our global village. Neither are they mostly "immoral adults," receiving the just reward for their sexual sins as some would like to believe. Many of them are children whose only error is being born and trying to survive.

What should we do?

Faced by the enormity of the AIDS disaster, it is easy for individuals to feel powerless, to wonder what, if anything, a single person of limited means could do that would count. Yet the truth is there is much that individuals and small groups can do, either directly or indirectly. Some of the things we can do include:

[8] www.clintonfoundation.org

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Raising our voices on behalf of children

The International Convention on the Rights of Children (ICRC) identifies two classes of actors in the provision of rights to children: “claim holders” and “duty bearers.” Where AIDS is concerned, we can say children are the claim holders of the right to care, protection and life with dignity. On the other hand we are the duty bearers, those charged with the responsibility to ensure that children enjoy these rights. By speaking out on behalf of children we remind all duty bearers, including ourselves, that we have a critical responsibility toward children.

Canadians are fortunate to have a government that is largely responsive to the expressed feelings of its population. Thus when Canadians rallied against pharmaceutical companies and their policy of withholding AIDS drugs from those who could not pay, the government passed Bill C-9 in 2004 to provide for the manufacturing of cheap generic versions of these drugs. Many recent government actions to support HIV/AIDS globally[9] can be traced to such expressions by groups or individuals. The key, however, is that we have to speak out, before the government can act. Pressing the government to do more in addressing the impact of AIDS on children in Africa is one of the most useful actions we could take on behalf of children. Many Canadian international NGOs have responded to the urgent need for actions to stem the AIDS disaster. One way they do this is by organizing forums and events to keep alive the dialogue with Canadians and the government on the need to stay engaged at every possible level. Some of these events offer platforms for individuals to become direct participants in this effort.

Supporting the provision of affordable ARV drugs for mothers and children

The availability of life-saving antiretroviral drug regimes and therapies in the West has demonstrated the fact that AIDS is no longer the automatic death sentence it was once seen to be. The WHO has put the provision of ARVs at the centre of its effort to combat the AIDS epidemic, through the “3 by 5” program. UNAIDS has recently released the “AIDS in Africa: Three Scenarios to 2025”[10] report, an attempt to predict the long-term impact of the epidemic on sub-Saharan Africa. It is clear from this report that the mass provision of affordable ARVs is the key to realizing any positive turnaround for the AIDS disaster. The cost of these drugs has fallen drastically in the past 10 years, from an average of $10,000 a year to less than $200 in some cases[11]. Therefore, the biggest barrier to providing ARV drugs has moved from their high cost to the political will to act as well as the challenges of ensuring their safe and effective delivery.

The provision of these drugs has an added value to children that does not normally pertain to adults. They extend the lives of parents and in this way postpone the incidence of orphanhood. The psychological value of having a living parent, especially the mother,

[9] These include increased support to the Global Fund and IAVI and even the decision by CIDA to allow the use of its resources to go towards paying for treatment programs for AIDS sufferers.
[10] UNAIDS: www.unaids.org
[11] An Indian generic drug manufacturer, CIPLA, announced in 2004 that they could supply ARV drugs for less than $150 per person per year.

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cannot be overestimated. Neither can the damage sustained by the child who loses the support of a parent be measured, as any person who has lost a loved one can attest. In much of Africa, where women shoulder over 70 per cent of the burden of raising children, caring for families, growing food and other economic activities, the loss of a mother can hit a family especially hard. Because the incidence of death from AIDS is disproportionately affecting more women than men, this creates the historically unprecedented situation where more children are losing their mothers than are losing their fathers[12]. Specific actions to help keep parents alive include: encouraging the government to increase support to programs and organizations set up to provide affordable and safe antiretroviral drugs to the largest number of people; demanding that the government earmark at least 20 per cent of the resources allocated to HIV/AIDS for programs targeting orphans and other vulnerable children etc. This would fund, among others, programs that extend parent-child relationships.

The government of Canada should be commended for passing Bill C9. But it needs to be reminded that this bill contains no provision for the production of pediatric ARV drugs. Guidelines and mechanisms that will guarantee such drugs are produced for children should be put in place if the legislation is to have the desired impact on the most vulnerable. Similar pressure should be brought to bear on the drug industry to allocate sufficient resources for research in better drugs and dosages for children and simpler modes of administering them in resource-poor countries.

Supporting programs that give orphans and vulnerable children access to critical services like health, nutrition and psychosocial care

No government in the affected countries has the resources to provide institutional care for all the millions of children who have or will become orphaned by AIDS. The strengthening of community and extended family systems to enable them to shoulder the added burden of caring for these children is the only strategy that has a reasonable chance of long-term success. This must include the creation of legal regimes that provide orphans protection from abandonment, exploitation and abuse.

Psychosocial support is deemed a very important component in the continuum of care that these affected children require. Such care is rarely provided because few organizations have the skills or resources to do so. The regimented community development models that development agencies have created are not suited to the delivery of such "intangibles." We shall have to learn how to do this over time. In the meantime, such care can be given through acts that demonstrate our will to share not only our resources but also our time, our spirit, our complete selves, through visits, prayer, writing or other ways of maintaining contact and communion with the affected. It is hard to step into the gap left by a departed parent, impossible to replace such a loss, especially from thousands of miles away. But even small acts which tell the victims they are not

[12] UNICEF defines an orphan as a child who has lost either a mother or both parents. Analysis of orphan data in 2003 showed that, by this definition, the number of children recognized as orphans is increasing rapidly in Africa because more women are dying from AIDS than men.

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alone have great value as they minimize the pain of loss and aid the individual on the path to recovery.

Education

The provision of access to quality affordable education for children in countries ravaged by AIDS is not merely a desirable goal but a social survival necessity. Education provides the skills to replace the many professionals and other skilled manpower that these countries have lost. On a more basic level, schools also have the potential to serve as surrogate parent substitutes—as many already do—by providing children with a safe environment and with credible role models to emulate and learn from. Keeping children in school keeps them out of trouble. It keeps the hope alive that, despite the tragic way these children's lives have started, they will end differently.

The most important thing that the world can do for the children who have lost their parents to AIDS is to ensure that they receive the education that will give them at least a fair chance at life. Ideally such education should be free and available to all. Removing the burden of education costs will make it much easier for grandparents, relatives and friends to cope with the role of becoming foster parents. It will also improve the life prospects for girls as keeping girls in school reduces the risk of sexual exploitation or risky sexual behaviour leading to infection or unwanted pregnancies. Some of the specific actions we can take to ensure the achievement of this goal include:

- Child sponsorship: Over the years, Canadians have contributed millions of dollars to support poor children through school. Most of this support is channeled through charity organizations, through child sponsorship programs. The need for such support is greater now than ever before.
- Lobbying Governments in the West to provide more resources to support the provision of education opportunities on a sustained and long term basis. Such measures include linking debt cancellation with the provision of education places to vulnerable children, especially girls.
- Other actions include asking the government of Canada to announce a program to fulfill the promise it made years ago to raise Canada's contribution of overseas development assistance to 0.7per cent of GDP. Such an increase, if well utilized, would have a huge impact on the lot of the very poor without affecting much the standard of living that Canadians already enjoy.

New models of sharing

The AIDS pandemic has elicited unprecedented generosity from the world community. Government and multilateral funding institutions have provided millions of dollars to help fight the disaster and promised millions more. However, support from individuals has been limited, not from a lack of desire to help, but because many people feel overwhelmed by the scale of the crisis and have little idea how they can best

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contribute. In strategizing on the best ways to combat AIDS, many experts have recognized the need to strengthen the health delivery systems of affected countries as the best way of guaranteeing continued quality care and the safe delivery of ARV drugs. Similar recognition has been given to the need to improve legal and other protection systems. In addressing the social impact of the pandemic, it is important to appreciate the need to create appropriate community structures that will be used to channel the resources available and to support the long-term care and social reintegration of all people affected, including children.

This raises challenges as well as opportunities. There is the challenge of harnessing the good will expressed by individuals in Canada to help by giving money, materials and their own time and skills. There is the challenge of establishing effective partnerships between the many community-based groups that that have risen up in Africa to confront AIDS with Canadian groups and individuals who want to help. These challenges, if well addressed, will present us with opportunities to share ideas, experiences and stories of what has worked and what has not. By creating a real chance for Canadians to become directly involved in such an important undertaking, we shall be expanding the international development space to include individual contributions, as opposed to now where development actors are largely limited to governments, private sector, NGOs, civil society and other organized groups. If this is what it will take to defeat AIDS, then this tragic story may have a happy ending after all.

Conclusion

The description of HIV/AIDS as a humanitarian disaster is an apt one, as is the application of a disaster response model as the key strategy with which to address it. However, the success of this strategy is threatened by the failure of key actors to prioritize effort and resources to children and on the many and different ways that the HIV/AIDS pandemic impacts them. This oversight not only makes real success today very unlikely, but also reduces the prospect for sustaining any gains we make into the future, since it is primarily today's ignored children who will live in it. Canadian people and organizations have an important role to play in correcting this problem by getting involved directly and indirectly, by pressing important duty bearers like the government and other institutions to do their part. Many Canadians are already doing this, while many more would like to play a concrete part in this historic human enterprise to roll back a disaster that threatens us all.

The challenge is to create models and opportunities through which such good will can be translated into sustainable actions that benefit the most affected—especially orphans and other vulnerable children.

Ndungu Kahihu is the HIV/AIDS Advisor and Program Manager for Save the Children Canada.

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