FORUM
FOR APPLIED RESEARCH AND PUBLIC POLICY

Energy, Environment and Resources Center
The University of Tennessee
311 Conference Center Building
Knoxville, TN 37996-4134
Phone: 423 974-4251 • Fax: 423 974 8431
Email: forum@ezrc.gw.utk.edu
Home Page: http://forum.ra.utk.edu

June 1, 1999

Sandra Thurman
Director
White House Office of
National AIDS Policy
Washington, D.C. 20503
~~202-456-7200 phone~~
~~202-456-7311 fax~~

736 Jackson Place
202-456-2959 (phone)
202-456-2439 (fax)

Dear Ms. Thurman:

In an upcoming issue of *FORUM for Applied Research and Public Policy*, we plan to publish a series of articles on the future of children in the next century. The lead article for the section will be written by Dr. Kenneth Jaffe at the International Child Resource Institute. Other invited authors include Dr. James Garbarino at Cornell; Miriam Edelman at the Children's Defense Fund; Charles McCormack of Save the Children; and President Jimmy Carter. I'm writing to ask if you would like to join them by contributing an article on the effect of AIDS on children.

The approach to the article is up to you, of course. However, you might want to explain how many children are—and will soon be—affected by AIDS around the globe. What prevention efforts must be mounted to slow the spread of the disease? How severe is the epidemic in Africa? What could the United States do to help care for the affected families? These are the kinds of issues that *FORUM* readers would find of interest.

As for logistics, the article should run about 2,500 to 3,000 words (10-12 double-spaced pages) and would be due in draft on July 20, 1999.

Because you may be unfamiliar with *FORUM*, I have provided the following brief description of the publication. *FORUM*, which is now in its 14th year, is published by The University of Tennessee, TVA Rural Studies, and the Oak Ridge National Laboratory. It seeks to examine a broad range of policy issues related to economics, environment, energy, and science and technology. *FORUM's* editorial style is designed to reach a broad and diverse readership, ranging from academics to research analysts to staff members of Congress.

Over the past decade, *FORUM* has won more than 30 awards for editorial excellence from such

organizations as the International Academy of Communications Arts and Sciences, the International Association of Business Communicators, the International Association of Technical Communication, and the National Association of Government Communicators.

Even more important, *FORUM* has been able to attract some of the most important people in their fields, including former Secretary of Education Lamar Alexander; former Secretary of Energy Hazel O' Leary; Stephen Schneider of Stanford University; Senator Daniel Patrick Moynihan; Doris Meissner, head of the U.S. Immigration and Naturalization Service; and Samuel Broder of the National Cancer Institute.

Please give me a call to let me know if would like to participate in this symposium. I can be reached by phone at 423-974-4718; fax 423-974-8491; or e-mail lmoist @utk.edu.

Sincerely,

Linda Moist

Linda S. Moist
Managing Editor

423-974-4566(p) 423-974-8[illegible]f)
Elise LeClaire

FORUM
FOR APPLIED RESEARCH AND PUBLIC POLICY

Energy, Environment and Resources Center
The University of Tennessee
311 Conference Center Building
Knoxville, TN 37996-4134
Phone: 423 974-4251 • Fax: 423 974 1691
Email: forum@ercd.gw.utk.edu
Home Page: http://forum.ra.utk.edu

September 1st

June 1, 1999

Sandra Thurman
Director
White House Office of
National AIDS Policy
Washington, D.C. 20503
~~202-456-7300 phone~~
~~202-456-7311 fax~~

736 Jackson Place
202-456-2959 (phone)
202-456-2439 (fax)

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423-974-4566(p) 423-974-8491(f)
Elise LeQuire

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OFFICE OF NATIONAL AIDS POLICY

EXECUTIVE OFFICE OF THE PRESIDENT
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RE: Sandra Thurman article

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NOTES/COMMENTS:

Many, many thanks for your patience. Please call me (202-456-2959) if you have any questions.

Cheryl

736 Jackson Place
Washington, DC 20503
(202) 456-2437
(202) 456-2438 (fax)

CHILDREN AS A CATALYST FOR A MORE COMPREHENSIVE FIGHT AGAINST HIV/AIDS: LESSONS FROM AFRICA

By Sandra L. Thurman
Director, Office of National AIDS Policy
The White House

In Africa, the common belief is not that we have inherited this world from our parents, but that we have borrowed this world from our children. Our solemn obligation is to return to them a better world, where pain and suffering have been diminished and where hope and opportunity blossom. Yet we are in so many ways failing, giving them back a world where poverty and disease eclipse those rays of hope. We have an entire generation in jeopardy, and chief among their enemies is AIDS.

As a nation, we have just begun to realize that the AIDS epidemic here in the United States is only a small wave of the AIDS pandemic sweeping the globe. Sub-Saharan Africa remains the epicenter of this crisis, with 22.5 million—or two-thirds—of the 33.4 million worldwide annual infections occurring in this region. By the end of the next decade, over 40 million children will have been orphaned by AIDS worldwide – 95% in sub-Saharan Africa.

In light of these staggering numbers, a focus on children can and should be a catalyst for a more comprehensive fight against AIDS. Twice this year, I have visited South Africa, Uganda, and Zambia at the request of President Clinton. Together with leaders from Congress and the private sector, we went to bear witness to the AIDS emergency and to search for ways to enhance our understanding and support for sustainable solutions through the lens of children orphaned by AIDS.

Those of us who have worked on the front lines of this country's early epidemic have seen more than our share of sickness and death, loss and grief. It has been a sad preparation for

those of us who have seen the epidemic in Africa, though there is nothing that can prepare you for the loss and pain in the eyes of a child who has lost everything to AIDS. The faces of so many children and families devastated by AIDS are seared into our memories.

While many of us have witnessed the ever-evolving impact of AIDS on the urban and rural centers of the United States, it is almost impossible to grasp the grip that AIDS has on communities around the world. In Africa, where the grip is especially tight, AIDS is now the leading cause of death among all people of all ages. Each day, AIDS buries more than 5,500 women, men, and children and 11,000 people are newly infected – one every 8 seconds. While AIDS in sub-Saharan Africa is an equal opportunity killer, women, children and young people are increasingly caught in its path.

In the United States we have made and continue to make great strides in the prevention and treatment of HIV and AIDS. Our investments in research have given us tremendous new therapies that—while far short of a cure—have helped many to live much longer and better lives. Many of our friends and loved ones who had all but given up hope have been pulled back from the brink. Yet the good news enjoyed by some has left too many of us to believe that the worst is behind us. The sobering truth is that the AIDS epidemic is far from over.

We must remember that the tragedy of AIDS is *not* slowly nearing its end here or anywhere else in the world. On the contrary, it is just beginning to unfold. Here in the United States, infections continue at some 40,000 to 60,000 per year; many already infected do not know their HIV status; and, many who do still go without care.

In most other countries where AIDS has taken hold, the news is far more grim. The treatments that have helped so many here are a distant dream. Africa, as an epicenter of this plague, has suffered the most. And the severity of the current AIDS pandemic will not be limited

to the African region. Indeed, as goes Africa, so will go India, Southeast Asia, and the newly independent states of the former Soviet Union.

AIDS Orphans

In a host of different ways and from a variety of different vantagepoints, it is our children who are caught in the crossfire of this relentless epidemic. There are many places throughout the sub-Saharan African region where up to one-quarter of all children are already living with an HIV-positive parent—in nine sub-Saharan African countries, between one-fifth and one-third of all children will be orphaned by AIDS by the end of this year.

The numbers are staggering, but they don't tell the whole story. The intrusion of AIDS into households and communities across sub-Saharan Africa has left millions of children without the protection, love, and care essential to their well being. Those who lose a parent to AIDS are commonly met with stigmatization, social isolation, and prejudice. Besides this significant psychosocial distress, these children also suffer from neglect, malnutrition, loss of schooling, forfeiture of inheritance and increased exposure to crime. They are also at extraordinary risk of physical and sexual abuse as well as child labor exploitation. The result is a vicious cycle of poverty and segregation that places these children at greater risk of contracting HIV themselves and effectively unravels years of progress in economic and social development.

In Lusaka, Zambia alone, 100,000 children are estimated to be living on the streets. Most of these children have been orphaned by AIDS. They spend their nights on Cairo Road, sleeping in gutters and in trees, hoping to remain out of the "line of fire." Some are new to the streets, while others have called it home for years. The longer they stay, the harder they get, and in an effort to survive too many are forced into crime, survival sex, and drug trafficking. While none

of these children would actually "choose" this life, once they "belong to the streets" it is difficult to turn back. Though good data are lacking, it is likely that HIV infection is spreading rapidly among these children.

AIDS in sub-Saharan Africa is also placing extraordinary burdens on the extended family and village systems that have always been the backbone of African child-rearing tradition. At the same time, the responsibility of care for children orphaned by AIDS is stretching government and community resources to the breaking point. Traditionally, the extended family has met the basic needs of orphans and provided a protective environment in which they could grow and develop. However, AIDS has threatened the stability of these time-honored kinship networks, which can no longer guarantee the long term care of orphans.

Increasingly, heads of households are either very old, or very young. Take Bernadette Nakayima, a grandmother from a small village called Kyahusome outside of Maskaka, Uganda. When we met, Bernadette had lost 10 of her 11 adult children to AIDS and, at age 70, is now caring for all 35 of her grandchildren. Buoyed by a grandmother's love and aided by loans from a village banking system, she supports this large family by growing sweet potatoes, beans, and maize, raising goats and pigs, and trading in fish, sugar, and cooking oil. With the money she earns, she is able to send 15 of her grandchildren to school, provide modest treatment for the 5 who are now HIV-positive, and begin construction on a house big enough to sleep them all at the same time.

And as if survival alone was not enough of a burden, she devotes some of her spare time to an organization called "United Women's Effort to Save Orphans." Founded by the First Lady of Uganda, Janet Museveni, UWESO helps link in solidarity thousands of women who share Bernadette's struggle.

The growing number of children orphaned by AIDS will have a profound impact on society. Eventually comprising up to one-third of the population under 15 in some countries, this sad part of the AIDS epidemic represents a generation in jeopardy – a sea of youth who are disadvantaged, vulnerable, undereducated, and lacking both hope and opportunity. The creation of such a large and disaffected demographic "youth explosion" could propel some of these societies to significant unrest and destabilization over the long term. The threat to the prospects for economic growth and development in the most seriously affected countries is considerable. Community-based and multi-sectoral strategies to provide care and support for orphans and children affected by AIDS should be at the center of our efforts to combat this global pandemic.

Mother To Child Transmission

Compounding the tragedy of children orphaned by AIDS are those that are also living with AIDS, many of whom were infected through the mothers they have lost. Ten percent of all new infections in Africa occur through mother-to-child transmission during pregnancy or through breastfeeding. In sub-Saharan Africa, nearly 600,000 new infections occur each year among infants. In Africa today, for every ten children born to HIV-positive mothers, two become infected during delivery and one becomes infected through breastfeeding.

The prognosis is grim. Indeed, AIDS is reversing years of progress in child survival. In the next ten years, in many Africa countries, infant mortality is expected to double, child mortality will triple, and as we move into the new millennium, one in three children in Africa will be orphaned by AIDS.

As such, developing methods to reduce mother-to-child transmission of HIV that are feasible in Africa is a high priority. For the past three years, multiple studies have been initiated

to find interventions that could be utilized in poor countries. In February 1998, data from the first of these studies demostrated that a short course of zidovudene (AZT) could reduce mother-to-infant HIV transmission by nearly 40% in non-breastfeeding infants. Even more recently, on July 14, 1999, the National Institutes of Health announced that a joint Uganda-U.S. study had demonstrated the efficacy of a low cost drug called nevirapine in reducing mother-to-child transmission of HIV at birth by an additional 50% as compared to the short course of AZT regimen.

These preventative drug regimens are far simpler and less expensive than the antiretroviral regimens used in the United States, and potentially just as effective. These may give pregnant women a new incentive to seek HIV testing and counseling, and if infected, to receive treatment where it is available.

New developments that reduce the risk of mother to child transmission are extremely encouraging and provide hope for being able to save the lives of hundreds of thousands of babies a year. However, a host of additional issues need to be explored and addressed before this knowledge can be effectively translated into productive action. For example, to receive maximum benefit from AZT and perhaps NVP, mothers are encouraged not to breastfeed. In cultures where breastfeeding is the norm, women who choose not to breastfeed are often assumed to be HIV-positive, and are thus faced with stigmatization based on their perceived HIV status.

Furthermore, in many areas of sub-Saharan Africa, infant formula is unaffordable and lack of clean water often makes it unworkable. In some cases, babies are as likely to die from diarrhea resulting from incorrect use of formula as they are from AIDS. These technical and ethical challenges deserve our immediate and urgent attention, so that the promise of exciting new technologies can become a reality for as many women and children as possible.

Barriers To Effective Prevention And Care

There are numerous barriers to effective HIV prevention, and care and treatment for those already living with HIV and AIDS. In order for prevention and care efforts to truly take hold, several underlying issues - including health care infrastructure and stigmatization of those living with HIV/AIDS - must be addressed. The experience from Africa has shown us that responses to these factors must be incorporated into plans to address the epidemic in any society.

The lack of health care infrastructure is a serious obstacle in Africa. At least 95% of pregnant women do not know they are HIV-positive and currently lack access to the testing and counseling services needed to find out. In many areas, most women deliver their children with the assistance of midwives in their homes, or in makeshift clinics currently unequipped for complex interventions. In the poorest parts of Africa, nearly 80% of women lack access to any kind of health care at all.

Governments remain under intense pressure to provide basic supports, with the problem of children left behind by AIDS just one of many competing urgent priorities in developing countries. Strains on already limited resources leave most public safety nets for children uncoordinated, under-funded, and unavailable to the majority of those in need.

Like the dark days of this nation's struggle with AIDS, many African communities shroud the all-too-frequent funerals with a shroud of silence. The stigmatization of AIDS can be so overwhelming that just the fear of discrimination, violence, and abandonment can dramatically restrict the ability of women to make safe choices. Recently, an HIV-positive woman in South Africa went public with her status and was stoned to death by her neighbors.

Countless other women and children have been left destitute after their husbands discovered, or decided, that they were HIV-positive.

When denial fades, community mobilization enables those involved to believe that they can change their circumstances for the better. This sense of possibility is a powerful behavior change tool.

Moving Forward

Increasingly, the impact of AIDS is reaching far beyond the world of public health. AIDS is not only causing unfathomable human suffering, it is jeopardizing economic growth, political stability, and civil society in many sub-Saharan African nations. Just as AIDS can overwhelm the body, it can overwhelm a nation. To effectively address this epidemic, we must engage leadership from all sectors of government – from the health sector, to the economic sector, to the labor sector, to the military sector.

To support this kind of multi-sectoral response, the Clinton Administration has launched a broad new initiative, entitled Leadership and Investment in Fighting an Epidemic, or LIFE. The centerpiece of this initiative is a $100 million investment in the FY2000 budget to implement a four pronged strategy- prevention, including the prevention of HIV transmission from mother to child, basic care and treatment, support for children orphaned by AIDS, and development of the infrastructure needed to accomplish these goals. The plan represents an unprecedented collaboration between the U.S. Department of Health and Human Services, Department of Defense and Agency for International Development.

This is the largest-ever increase in U.S. support for fighting the global pandemic. It will more than double our investment in HIV prevention and AIDS care and treatment in Africa. While it is just a first step, this initiative is an essential foundation for progress in garnering resources that parallel the magnitude of this rapidly escalating pandemic. The enormity of the global AIDS pandemic necessitates a coordinated response. The United States government cannot and should not do this alone.

The LIFE initiative will galvanize an enhanced response from the other key stakeholders. The U.S. will increase its dialogue with the political leadership in countries hardest hit, challenge other developed nations to match this increased commitment, and maximize its coordination with multi-lateral institutions, the private sector, and the many NGOs working in the most heavily impacted regions.

Lessons For The Future

Painful experiences here at home and in Africa have taught us valuable lessons. Most important for the future of our global community is the understanding that we are much more alike than we are different. While we must celebrate our diversity, there is much we can learn from each other. We are far more than just a collection of independent countries. As a family of nations, our fates are inextricably linked. The AIDS epidemic in Africa, and throughout the world, is our shared epidemic.

We must also understand the remarkable power of real and sustained political leadership. While the struggle against AIDS will continue to depend on the valiant efforts of dedicated individuals in communities worldwide, it cannot be won without leadership from the top. Clear and concerted political commitment to speak the truth about this epidemic and to allocate the

resources needed is essential. In countries that have instituted successful HIV prevention strategies—such as Uganda and Senegal—political commitment from the highest levels has made the critical difference.

Partnerships are also essential. AIDS is not just a health problem but a development problem, a trade problem, a democracy and civil society problem, and a security problem as well. AIDS is everyone's problem and everyone must be part of the solution.

Finally, truth matters. Thousands have paid the ultimate price for the stigma that surrounds AIDS. Together, we must lift the shroud of secrecy that surrounds AIDS so that individuals and families living with AIDS will no longer be forced to suffer in silence. For years in America, AIDS remained underground. People living with AIDS lost their jobs, their homes, their health insurance, and their dignity to the fear mongering and finger pointing of others. Leadership, education, and expansion of civil rights laws have helped—though there remains much work left to be done. AIDS thrives in darkness and secrecy, and shrinks from the light of truth.

Much has been written about what we need to do to turn the tide of this epidemic. It is now time to move from paper to practice and from words to deeds. Together, we must find ways to affirm that we are a global community and to join our battles against AIDS in America, in Africa, and around the world in a shared campaign. As Archbishop Desmond Tutu has said, "If we wage this holy war together – we will win."

We are living in a time of great challenge. The destiny of millions hangs in the balance. We cannot afford to squander the loss of the nearly 14 million people around the world we have lost to AIDS, but instead must build from this tragedy a foundation of hope, a legacy of compassion, and a partnership forged by a shared struggle. Our children deserve no less.

OFFICE OF NATIONAL AIDS POLICY

EXECUTIVE OFFICE OF THE PRESIDENT

THE WHITE HOUSE

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736 Jackson Place
Washington, DC 20503
(202) 456-2437
(202) 456-2438 (fax)

August 23, 1999

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The University of Tennessee
311 Conference Center Building
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Sandra Thurman — Office of National AIDS Policy, The White House
Printed name — Street Address

736 Jackson Place, NW — Washington — DC — 20503
City — State — Zip

(202) 456-2437 — (202) 456-2439 —
Telephone — Fax — Email Address

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Signature: Sandra S. Thurman — Date Dec. 8, 1999

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