NATIONAL COMMISSION ON AIDS

Report Number Three:

Research, the Workforce and the HIV Epidemic in Rural America

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President George Bush
The White House
Washington, DC 20500

Dear Mr. President:

Since our last report to you, the National Commission on AIDS has traveled to rural Georgia to better understand the impact of the HIV epidemic in rural communities across the country. Two formal hearings have examined the current status of HIV research and drug development and looked at the mounting hardships which shortages in health care personnel are imposing on people with HIV infection and AIDS. A working group of the Commission also met with public health officials and others from the Southwest region of the country in Dallas and heard poignant testimony about the lack of many basic publicly supported services needed by people affected by the HIV epidemic. The enclosed report highlights the National Commission's most recent findings. Again it contains a short series of recommendations for swift action.

Sincerely,

June E. Osborn David E. Rogers

June E. Osborn, M.D.
Chairman

David E. Rogers, M.D.
Vice Chairman

cc: The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of
Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of
Representatives

The Honorable Robert H. Michel
Minority Leader of the House of
Representatives

NATIONAL COMMISSION ON AIDS

Report Number Three

AIDS IN RURAL AMERICA

OVERVIEW

The number of new AIDS cases diagnosed in rural communities across the country is growing at an alarming rate. Although the epidemic continues to be most severe in urban areas, there has been a 37 percent increase in diagnosed AIDS cases in rural areas compared to a 5 percent increase in metropolitan areas with populations of over 500,000 in just a one year period. In Georgia the number of AIDS cases has tripled in the past two years. For the first time, the spread of disease in rural Georgia and small cities has equalled the growth of HIV infection in metropolitan Atlanta.

This is happening all across the country. The Commission was told of alarming rates of increase in HIV infection in Arkansas, Mississippi and rural communities in Texas. It is happening tragically and secretly without adequate health care services or human support in these rural areas.

FINDINGS

- In rural America, there is an epidemic of fear and bigotry, fanned by the absence of education and knowledge, surrounding HIV infection and AIDS. Like much of urban America, rural communities are just beginning to confront the realities of HIV infection and AIDS. The fear of being "found out," we were told, is almost as great as the fear of the disease itself. As one Commission member, Belinda Mason, noted, "I have seen rural America at its warm, supportive best and at its close-minded, bigoted worst."

In one community we learned of a young man who sneaks out to his mother's car at night, covers himself with a blanket and waits for his mother to come out at dawn to drive him many miles to another county where he can receive treatment anonymously. When he returns home he remains in the car covered by the blanket until sundown when he creeps back into his mother's trailer home. All this, to prevent others from knowing that his mother is housing and caring for a son who has AIDS. Little will be known of his life — only that he died of AIDS.

One man told us of being "thrown out of my church and told not to come back." A local doctor told us, "We've had people lose their jobs and get kicked out of their apartments." Another told us, "President Bush talks about those thousand points of light, but whenever people hear that I have HIV, the lights go out and I am in the dark."

In Texas we were told that the isolation and stigmatization of people with AIDS in rural areas is similarly severe. "Even a family is apt to reject the patient because of fear that the neighborhood or community will respond hatefully."

- AIDS education is virtually non-existent and desperately needed in rural communities. This includes even the simplest of education about HIV infection for health care providers. Ignorance and misinformation are seriously hampering if not crippling efforts to treat those who are sick; clearly contributing to the rapid increase in rates of HIV infection in rural America; and contributing greatly to the discrimination against and ostracism of people living with HIV infection and AIDS.

Drug education, prevention, and treatment programs range from grossly inadequate to non-existent. If there is to be any hope of stemming the tide of what one health official described as "three epidemics - AIDS, drugs and STD (sexually transmitted diseases)" - services for all of these disease problems and educational programs designed to contain them must be dramatically expanded.

One infectious disease specialist from Macon, Georgia expressed great concern about the spread of AIDS into families, noting that he was currently seeing five families in which both parents are infected with HIV. The growth in the number of heterosexual cases of AIDS, in rural communities, particularly among women, (many in their teens), is often attributed to the combination of crack cocaine, trading sex with multiple partners for drugs or money, and rising rates of syphilitic infections which seem to increase transmission of HIV infection. In the last five years, the number of new cases of syphilis has increased tenfold in Southeast Georgia.

- The singular lack of access to primary health care services in rural America was shocking and heartrending. The Commission's first-hand look at rural communities made graphic and personal reports of "a rural health care crisis evidenced by rising rural maternal and infant mortality rates, lower health status of rural Americans compared to those living in cities, [and] a greater proportion of rural Americans lacking any health insurance" (Senate Report 101-127). AIDS is dramatically accentuating the problem.

In Macon, Georgia, the Commission visited the Bibb County HIV Ambulatory Clinic where health care providers were virtually overwhelmed with the increasing number of people with HIV infection and AIDS needing treatment and support services. As the need for services increases, the dollars decrease. The Bibb County HIV Ambulatory Clinic, operated by the Bibb County Health Department, receives no direct financial assistance whatsoever from the federal government. Given the rising demand for services this can no longer continue. Federal assistance is essential for this clinic and other similar clinics serving the growing numbers of people living with HIV infection and AIDS.

HIV RESEARCH AND DRUG DEVELOPMENT

OVERVIEW

On May 7 and 8, the Commission convened hearings to review the current status of HIV-related biomedical research efforts and the status of new clinical drug trials. Representatives from the National Institutes of Health (NIH), Institute of Medicine, ACT UP, the American Foundation for AIDS Research, Project Inform, American Association of Physicians for Human Rights, and others were invited to report to the Commission on their ongoing efforts to support and monitor private and public HIV-related research efforts. The Commission will continue to rely on these organizations, with expertise to carefully examine many complex scientific issues, to keep us apprised of research efforts and findings.

While the investment of public and private funds into HIV-related research is impressive, and the fundamental biomedical knowledge about HIV infection acquired over a very short time remarkable, the transfer of knowledge and treatment to those who are HIV infected falls far short of the mark. To put it bluntly, the number of people involved in clinical trials (12,000) versus the number of people eligible for clinical trials is pitifully small. The ground rules for trials seem often too rigid to permit many (such as drug users) from being included. People of color, women, and children are grossly underrepresented in federally financed trials. This limits access to experimental therapies as well as basic health care services many receive only through participation in trials. Communication between researchers, people living with HIV infection and AIDS, and the public is not being done well, accentuating all the problems noted above. Much of the blame for many of these problems rests with academic health centers. These centers and the federal government must do better. A clear, crisp, well articulated clinical research strategy is simply not in evidence.

Also grossly apparent is that many people seeking access to experimental therapies are simply not getting basic health care services for HIV-infection and AIDS. Clinical trials cannot exist or be productive in a health care vacuum. They must be part of a comprehensive health care system which ensures adequate access and reimbursement for all kinds of care needed, including experimental therapies for HIV-infection and AIDS.

FINDINGS

- Opportunistic infections are usually the cause of death for people with AIDS, yet the NIH has been slow in expanding its AIDS-related research activities to include research on drugs to manage opportunistic infections. The Commission agrees with all those who have called for a greater priority to be given to research related to these infections without slackening research on drugs to treat HIV infection and AIDS. Clearly, both are vitally needed and the dollars to ensure both are essential.

- Severe criticism was repeatedly expressed about the lack of results from the sizable investment (to date, approximately $428 million) in the AIDS Clinical Trials Group Program (ACTG). It was pointed out that the majority of FDA approved drugs for AIDS and AIDS-related opportunistic infections have all been developed outside the ACTG program.

Heated criticism about the limited number of participants in ACTG trials continues. Barriers contributing to the low level of participation in clinical trials, in addition to those already mentioned, include lack of adequate transportation, day care needs, exclusion of persons with hemophilia, and lack of access to basic medical services and clinical trial information. These barriers all demand aggressive attention and solutions, not more discussion.

- People of color are grossly under-represented in clinical trials. Approximately forty-three percent of all AIDS cases are seen in men and women of color. Yet only approximately 23 percent of the participants in clinical trials are men and women of color.

The Commission was told that this underrepresentation was of concern to the NIAID and that efforts were underway to increase minority participation in clinical trials. The Commission strongly supports these efforts and believes these efforts should be swift and carefully monitored to assure their success, with the results promptly reported to the public.

- Women, particularly women of color, have traditionally experienced difficulty qualifying for clinical trials. One witness told the Commission she has attempted to qualify for a research protocol for two years. "In this country," she said, "women have been secondary to men with AIDS, and most recently are secondary to babies."

According to the Chief of Perinatology at Harlem Hospital, "This historical precedent for excluding women of childbearing age from treatment trials can no longer be allowed. On the other hand, including women, especially pregnant women, only for the sake of improving the outcome of the child, is also intolerable. Women have a right to be included simply because they are infected and are dying. No other reason is needed." The Commission emphatically agrees.

- For a parent whose child is diagnosed with AIDS and whose only hope lies in the child's participation in an AIDS-related clinical trial, the exclusion of children from trials certainly highlights one of the gross inequities in our research programs. Since the early days of the epidemic, parents have been demanding that children be included in AIDS-related clinical trials and that parents and patient advocates be included in decisions about the care of their child.

Traditionally, children have been denied access to experimental drugs because of the unresolved ethical dilemma of whether or not to include children in trials. In fact, the Director of Pediatric AIDS Research at the National Cancer Institute told the Commission how efforts to increase participation of children in clinical trials were hampered by the lack of a national consensus on this major ethical question. Clearly, science has moved forward to where the inclusion of children in experimental therapies is essential.

The location of clinical trial sites and the availability of affordable transportation to them are crucial factors in making clinical trials accessible to children. We heard from one mother who traveled from Florida, to North Carolina and finally to Maryland before she could get her daughter into a clinical trial. We were also told that unless transportation is available and affordable it can be impossible for many people to travel even 45 minutes away from home. These are problems we can address and must address quickly.

- The Commission believes the NIH Community Program for Clinical Research on AIDS (CPCRA) is an imaginative and positive step. Because of a different philosophy and an aggressive grassroots impetus, these trials should help include people of color, women, intravenous drug users, children and other underrepresented communities in clinical trials. The Commission heard testimony from three physicians participating in the CPCRA program. All testified that the program would enable greater participation of people in trials at the places where they receive primary health care. "Clinical trials conducted in the primary care setting," according to one physician, "have access to large numbers of patients and are likely to fill quickly and finish as rapidly as possible." We also heard testimony from the National Hemophilia Foundation (NHF) about an ACTG-without-walls concept that demonstrates community programs do not sacrifice scientific value and integrity. The Commission strongly encourages continuation and expansion of the CPCRA program in parallel with the steps necessary to strengthen the ACTG's.

- Complaints were expressed about delays in the publication of clinical trial information. One witness urged all agencies sponsoring clinical trials in HIV/AIDS "to be more accountable to an anxious public, and that they actively and expeditiously release specific data concerning the results of their clinical trials."

- One impression needs swift settlement. We were also told that there currently exists a perception of conflict of interest for some investigators who play an advisory role with the NIH in setting national AIDS research priorities. One witness called on the Secretary of Health and Human Services "to mandate the full disclosure of all consulting relationships these investigators maintain with pharmaceutical companies." This deserves a prompt response from the Department of Health and Human Services.

SUMMARY

As is apparent, the Commission is worried about the status of clinical treatment trials. We are vividly aware of the enormous challenge confronting all scientists in developing new drugs and therapies for HIV and opportunistic infections. The obstacles are many and the successes, still sadly enough, are all too few. But the hope for thousands of people still rests with our clinical trial programs. Clearly these must be made more encompassing, more readily acces-sible to all, easy to find, well managed and well coordinated. There are many problems which need attention. We know they are being addressed but we can and must do better, swiftly and visibly.

PERSONNEL AND WORKFORCE

OVERVIEW

On July 18 and 19, the Commission convened a hearing to examine the personnel shortages which are hampering our response to the HIV epidemic. Physicians, nurses, dentists, social workers, allied health workers, volunteers, and representatives from the federal government and professional organizations presented the Commission with a picture of a national health care workforce confronted with increasing demands and decreasing support and re-enforcements. We were also reminded that unrealistically low health care reimbursement rates, especially rates for outpatient services, continue to serve as institutional disincentives for many health care providers to care for people with HIV infection and AIDS.

FINDINGS

Dentists

While there does not appear to be a national shortage of dentists, we heard repeatedly about a serious shortage of dentists willing to treat people with HIV infection and AIDS. We were told that since the early days of the epidemic many dentists did not treat people with AIDS because they were afraid and because they felt dentists had a traditional right to choose their own patients and refuse to see those who were suspected of or who openly admitted to being infected. "Happily," we were told by the American Dental Association, "not all dentists chose this avenue of escape, and the avenue has been closing as understanding of the disease has grown, as courts have declared this kind of behavior unacceptable, as dentists have become more comfortable with the disease and as their sense of moral and professional responsibility has replaced their initial fears."

While the Commission believes more dentists are willing to treat people with HIV infection and AIDS than in the early days of the epidemic, the number remains grossly inadequate and unacceptable. The difficulty, and in many cases complete inability, of obtaining dental services is still an all too common problem for people living with HIV infection and AIDS. One witness told us of only two dentists in his community who would accept Medicaid, neither of whom would see him due to his HIV infection. One dentist's excuse was that his office was carpeted and he would not be able to sterilize the room after the visit. The other dentist said she had plants and could not take the risk of him infecting her plants and her plants then infecting her other patients. That particular witness did find an oral surgeon who was willing to see him, but only if he would come after hours, come in the back door, and not tell anyone he had been there.

As one Commissioner put it, "Whether it is in rural communties or big cities, when it comes to dentists, I just keep hearing people with HIV infection and AIDS saying, 'I can't get help.'"

Nurses

The current nursing shortage continues to be of crisis proportions. The Commission heard testimony from experts who have studied the overall nursing shortage. It is clear to us the shortage promises to get worse in the future unless it is addressed now. We were told the Department of Health and Human Services and Department of Labor are predicting that the need for Registered Nurses will increase by 60 percent in the next 10 years. And, contrary to popular opinion, there is no untapped resource of trained nurses. One witness told us that only 4 percent of licensed Registered Nurses are working outside of nursing.

While efforts are underway to address the overall nursing shortage, special efforts are needed to better understand and address how the shortage is compounded by the HIV epidemic. Misinformation and fear about caring for people with HIV infection and AIDS and the considerable emotional strain that often comes with caring for people with HIV infection and AIDS are issues which must be confronted if we are to prevent nurses from avoiding the field.

Physicians

A shocking number of physicians are reluctant to take care of people living with HIV infection and AIDS. The New York Times recently reported that "with an estimated 200,000 people infected with the virus, New York City has more AIDS cases than any other city in the world. Still, the city's Health Department records show that 78 percent of local physicians and dentists have never done a single AIDS test. Although the city has about 25,000 physicians, the Gay Men's Health Crisis, the largest volunteer AIDS agency, has a referral list of just 45 qualified private AIDS specialists in Manhattan who are willing to take patients. There are only one or two for each of the city's other four boroughs which have half of the city's cases." Nationally, the Physicians Association for AIDS Care has a referral list of only 2,000 physicians, a tiny fraction of the country's total of 600,000.

One witness told us of a recent study that estimated only "10 percent of internal medicine residents have a strong commitment to the care of HIV infected people and are likely to include them in their post-training practice. About 25 to 30 percent have a definite aversion to HIV work and are planning their professional lives to avoid contact with these patients. The remaining 65 percent are neutral or uncommitted in their stance towards the AIDS epidemic."

Unwillingness or reluctance to care for people with HIV infection and AIDS is often attributed to fear of occupational risk and lack of adequate training and expertise in treating HIV infection and AIDS. The Commission believes both of these concerns should be acknowledged and addressed. Support at every institutional level is needed for education about occupational risks, training in the use of universal precautions, and the provision of adequate equipment. Support is also needed to develop a comprehensive HIV/AIDS educational strategy that effectively meets the needs of all physicians, particularly primary care physicians. After all, as one witness reminded us, if you consider that we have one million or more cases of persons infected with HIV across the country, it can no longer be acceptable for a physician or dentist to offer as an excuse, "I don't have expertise in relation to this particular disease." They simply must acquire the expertise.

Finally, we were told that "physicians who do not intend to work with HIV infected patients are characterized by negative attitudes toward people from predominant HIV risk groups, dislike working with an incurable disease which produces progressive loss of function and decreasing dependency, and a weak sense of professional responsibility." These findings certainly have important implications as we attempt to increase the willingness of physicians to work with people with HIV infection and AIDS, and to ensure access to care.

Social Workers

Many people living with HIV infection and AIDS have relied on social workers for much of their care. Social workers have developed many of the early models of AIDS services and community care and provided all levels of service for patients and families. The number of social workers across the country (500,000 in total) falls far short of the growing need. Social workers have long gone unsupported and unrewarded. It is time that changed.

Allied Health

Clearly, physicians, nurses, dentists, and social workers are not the only care providers in the HIV epidemic. Indeed, allied health workers do much of the hands-on care provided to people with HIV infection and AIDS. One witness pointed out there are 85 allied health professions, representing one-to two-thirds of the entire health workforce. These professionals are the hundreds of thousands across the country who draw blood, process HIV antibody tests, provide respiratory therapy, physical therapy, nutritional therapy and countless other health care services so many of us take for granted. There is a shortage of allied health professionals and, we were told, the shortage will be greater than the current physician and nursing shortage.

Public Health

The Commission also recognizes that there is an increasing need for public health specialists such as epidemiologists and biostatisticians. Nurses, physicians, dentists and others trained specifically in public health and often serving in community settings need support and re-enforcement. Schools of public health must expand and enrich HIV/AIDS specific programs in their curricula and training opportunities.

Volunteers

Volunteers are now and always have been at the heart of our response to the HIV/AIDS epidemic. They provide many of the services traditionally provided by paid professionals. "It is the volunteers," we were told, "who do the job, and most important in some ways it is the volunteers who save all of us millions of dollars every single year in this epidemic."

But all too often volunteers are viewed as a free resource, when in fact volunteers require financial and management support for recruitment, training and coordination. The cost effective dollars to train and support one of our most valuable resources in the HIV/AIDS epidemic simply must be given priority in government grants and agency operating budgets. In addition, one witness told us, something as simple and inexpensive as the President inviting AIDS volunteers to the White House would not only honor AIDS volunteers but would also send the message that our country is still in the midst of an HIV/AIDS epidemic and volunteers are key to the country's response.

Finally, the Commission heard from experts about the ethical dilemmas confronting health care workers in the HIV/AIDS epidemic. Concerns about occupational risk, duty to treat, the right to know a patient's HIV antibody status, emotional stress and strain, and assisting patients to make treatment decisions were all raised as difficult, sensitive issues that we must begin to confront and to assist health care workers to resolve. Caring for people with HIV infection and AIDS will challenge health care providers to overcome their fears, ignorance and prejudices. For many this will not be easy. But, as one witness reminded us, "We have taken on difficult tasks before." What we must do, he said, "is teach people a set of skills that we have largely ignored: how to relate to patients, how to understand their frame of reference.... We are defined by our patients and by the depth and breadth of care that we provide for them...we must encompass that when we become a professional."

It is clear to the Commission that effective AIDS education programs are needed for all health care workers. This includes those who are currently practicing, as well as those in training. We must support and re-enforce those who have chosen to provide the care and services needed over the last decade to people living with HIV infection and AIDS. We can no longer rely on what one witness called "people with a calling." By a personal demonstration of tolerant, less judgmental, more accepting, more compassionate, and more constructive attitudes toward all people living with HIV infection and AIDS, each of us could help this nation move more swiftly toward the changes that must come if we are to truly care for all people and control the HIV epidemic.

The Commission makes the following recommendations:

1. A comprehensive community-based primary health care system, supported by adequate funding and reimbursement rates, is essential for the care and treatment of all people, including people living with HIV infection and AIDS. The Commission highlighted this need in its first report and continues to believe that lack of access to primary care services provided by adequately trained primary care providers is undermining current efforts in HIV/AIDS research, prevention and treatment. The development of a comprehensive system with linkages to research protocols, existing community-based services, hospitals, drug treatment programs, local health departments, and longterm care facilities, based on a foundation of adequate support, is long overdue and should be a top priority for the federal government.

2. AIDS education and outreach services in rural communities should be expanded and designed to provide clear and direct messages about how HIV is and is not transmitted, and the kinds of behaviors that may place an individual at risk for HIV and other sexually transmitted diseases. Expansion of programs, resources and health care providers is also needed to respond to rural America's need for prevention and treatment programs that address the three epidemics of HIV infection, drug addiction and sexually transmitted diseases.

3. The NIH clinical trials program is in serious trouble. The limited number of enrollees in trials and the lack of demographic and geographic diversity of the participants threatens the success of the program and denies many people living with HIV infection and AIDS the opportunity to participate in experimental drug therapies. The academic health centers involved have not been as vigorous as one would hope in advancing these trials, nor has the NIH been vigorous in monitoring their performance. Aggressive efforts must be made to overcome the obstacles to participation for many who are under-represented. Success in this area can only be measured by increased participation in trials.

4. There is a desperate need for more research on the management of opportunistic infections, usually the cause of death for people with AIDS. The NIH simply must expand the level of research in this area. This expansion must not come at the expense of other research efforts and should be an integral part of a comprehensive AIDS research plan. This plan should outline the AIDS research priorities and goals for the entire NIH, and the resources needed to achieve them. The plan should be widely disseminated and should incorporate the views of persons living with HIV infection and AIDS.

5. There is a shortage of crisis proportions of health care providers capable and willing to care for people living with HIV infection and AIDS. This crisis will only get worse as the HIV epidemic continues into the 1990's. Action must be taken now to increase and improve the effectiveness of all programs designed to educate and retain practicing health care professionals, and to create incentives for providers to care for people in underserved areas. Existing programs such as the National Health Service Corps should be expanded. New programs such as those outlined in the Disadvantaged Minority Health Improvement Act (H.R. 3240) should be created. And, specific HIV/AIDS fellowships and training programs should be established and supported to prevent a crisis of greater magnitude.

6. Volunteers should be publicly recognized not only for the invaluable contribution they have made to people living with HIV infection and AIDS, but also for the way in which they fight fear and bigotry by fostering compassion and caring. The cost effective dollars needed to recruit, train, support and manage volunteers must be provided by the government and the private sector, and recognized as essential to our national response to the HIV epidemic.

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