

STATEMENT OF
C. EVERETT KOOP, M.D., Sc.D
SURGEON-GENERAL
U.S. PUBLIC HEALTH SERVICE
AND
DEPUTY ASSISTANT SECRETARY FOR HEALTH
DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Mr. Chairman and Members of the Subcommittee:

I am Dr. C. Everett Koop, Surgeon General of the U.S. Public Health Service. I am pleased to be able to be with you today to testify on the tragic problem of pediatric AIDS. Children are not only the most defenseless members of our society, they are also our gift to the future. Every one of us wants to assure their happy, healthy, and productive lives. Every one of us wants to solve their problems, or, in a utopia, to be sure they don't have any problems. Every one of us recognizes that AIDS in babies, with its devastating medical and social implications, must be among our highest priorities; it is a problem that must be met head on and controlled.

AIDS in children was first described in 1982, and significant numbers of infected infants have been diagnosed by doctors in New York City, New Jersey, and Miami, Florida. Since that time, the Department of Health and Human Services has sponsored a number of local and national meetings on pediatric AIDS, bringing together many experts to discuss the disease and to set a course for dealing with its consequences. Two things these experts agreed on from the very beginning were that infected infants and children and their families were subject to discrimination and were sometimes unable to obtain basic services. Participants told of a number of early efforts to provide care for these children and to eliminate discrimination.

Since the time of the first identification of pediatric AIDS, 595 cases of AIDS in children under age 13 have been reported to the Centers for Disease Control (CDC). We are developing an increasing knowledge base about this disease and about the numbers and characteristics of the affected children. The number of cases of children with AIDS has increased steadily over the last 5 years, but 85% of the cases of pediatric AIDS have been reported just since 1985. Many believe that the numbers are underestimated. In fact, doctors who see relatively large numbers of these patients say that only about one-third to one-half of the children with human immunodeficiency virus (HIV) infection meet the CDC definition for AIDS. Essentially, this is because that definition, and therefore our numbers of pediatric AIDS cases, do not include children with less severe symptoms.

At first, children with HIV infection were youngsters with hemophilia, who received the virus through transfusion or clotting factor before either mode of transmission was safe; i.e., before 1985. The second wave were children who received their infection from HIV-positive mothers, either through the placenta in utero or via the birth canal at the time of delivery. For 73% of those, the mothers are either IV drug users themselves or the sexual partners of IV drug users. This, of course, should come as no surprise, since 67% of all AIDS patients who are heterosexual are IV drug users or sex partners of IV drug users. 14% of the children with perinatally acquired AIDS were born to

women who come from areas such as Central Africa and Haiti, where there is a high level of heterosexual transmission of AIDS.

For several geographical areas in our country, the problem of pediatric AIDS is not just an appalling statistic; it is a fearsome reality that they face on a daily basis. 70% of the children with perinatally acquired AIDS are from the States of New York, New Jersey, and Florida. This reflects, of course, the close link between babies with AIDS and mothers who are associated with IV drug abuse or who are of Haitian origin. We do not expect, however, that pediatric AIDS will confine itself to these three States. The proportion of cases reported from other States is increasing; and, in general, it is safe to say that cities with large IV-drug-using populations can expect to see continuing increases in the number of HIV-infected children.

To prevent HIV infection in babies, we must prevent it in their mothers. To date, almost 3000 cases of AIDS have been reported in women. Almost all of these women are of child-bearing age. Epidemiologists project that the number of cases of AIDS in women will exceed 20,000 in less than 5 years, by the end of 1991.

Clearly, we must be sure that we are taking steps to prevent perinatal HIV infection. To achieve that goal, we must prevent infection among women, and we must counsel HIV-infected women before they become pregnant, about the possibility of giving

birth to an infected baby. This is an incredibly difficult task. The fact that women who have already given birth to a baby infected with the AIDS virus have more children is proof of how hard it is for people to change their behavior, even when they are faced with personally tragic consequences.

The Department of Health and Human Services has undertaken a number of activities designed to understand, deal with, and prevent pediatric AIDS. I want to tell you about some of them.

At the National Institutes of Health, research is under way to study the natural history of the disease, rates of perinatal transmission, and drug treatment for children with AIDS. Of the newly funded AIDS Clinical Study Groups (supported by the National Institute of Allergy and Infectious Diseases, NIAID), several will focus on pediatric populations. Studies with AZT in children are ongoing in the the NIAID-funded AIDS Treatment Evaluation Units (ATEUs) and in the National Cancer Institute intramural research program. The early results are quite promising: in several children who had either learning problems or some evidence of neurological impairment because of AIDS, all showed improvement after receiving AZT. // Shortly, several new studies will be undertaken to look at pregnant women at high risk of infection, or at women who are infected with the AIDS virus, to determine the risk of transmission from mothers to infants, to study the factors influencing the probability of transmission,

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and to try to ascertain when transmission of the virus is most likely during pregnancy. In addition, there is a new study planned by NCI and the National Institute of Child Health and Human Development to determine whether treating infected children with AZT in combination with gamma globulin will prevent the complications of HIV infection and perhaps prolong the lives of children who do become infected.

Recently, CDC awarded funds for several new pediatric projects, including studies to assess the rates of infection in young children in three high-prevalence geographical areas. Studies are also being undertaken to assess rates of infection in adolescents and to define more clearly high-risk behavior in this age group. Data from these studies will help us focus our prevention efforts. CDC is also launching a nationwide effort to determine the number of infected persons in the United States. These studies will be conducted in 30 U.S. cities and will include surveys of women of child-bearing age and newborns. Data from this effort will allow us to determine more accurately future health care and social service needs of children and women with AIDS.

The Health Resources and Services Administration (HRSA) last year began support of a program of Service Demonstration Projects, with funding to projects in the cities of Miami, Los Angeles, San Francisco, and New York. At the end of fiscal year 1987, HRSA

funded nine more Service Demonstration Projects in other high-incidence cities. These projects emphasize case management and a coordinated approach to caregiving, by bringing together local, State, and Federal resources to assist in health care delivery, family support, child care, housing, counseling, and referral to appropriate additional services. What we learn from these demonstration projects will be very helpful to us in assisting other States and localities to understand their needs and to respond to their problems, including the special needs of children with HIV infection. In addition, HRSA has funded four Education and Training Centers designed to train primary care providers, including pediatricians, in the diagnosis, management, and treatment of HIV infection.

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The Office of Human Development Services (OHDS) will soon publish a Coordinated Discretionary Grant announcement asking for proposals to demonstrate innovative approaches to providing child welfare services for infants and young children with AIDS. OHDS has earmarked up to \$1.2 million for each of the next three fiscal years for this activity. Up to six demonstration projects will be funded to establish child welfare services appropriate for infants and young children who have tested positive for the AIDS virus and whose parents are unable to care for them. Both foster family care and innovative community-based alternatives to hospitalization would be considered, along with day care, respite care, and other support services for caregivers. In addition,

grant recipients would develop educational materials for families, foster families, and staff of group homes. Those eligible to receive these awards might include a variety of public and nonprofit private agencies whose expertise and experience could be applicable to finding solutions to the problem of providing foster care and other services to children with HIV infection.

The Office of the Assistant Secretary for Planning and Evaluation is currently conducting a short-term exploratory examination of issues and practices regarding non-medical care for AIDS children. The purpose of this study is to help understand better who these infected children are and how they are being cared for. For example, we want to know how well the match is between the needs of these children and the services available to them, and how that is likely to change over time. Staff of the project will visit the three cities with the highest incidence of pediatric AIDS and the most experience in dealing with the problem. A report is expected in February 1988.

In another effort to expand our understanding of the problem, HHS officials from our regional office in New York met with individuals representing social service agencies in the States of New Jersey and New York. These meetings were extremely productive in terms of helping the Federal government understand the situation in these two severely affected States, and in

helping the State representatives recognize what Federal assistance and resources may be available. New Jersey, for example, was the first State to develop a Medicaid waiver for home and community-based services for persons with AIDS or AIDS-related conditions. Under this waiver, the State can use Medicaid funds to supplement foster family care rates for AIDS children. Combining Federal funds with State funds, foster parents caring for infected children receive between \$600 and \$750 per month, as compared with the \$400 to \$450 generally paid to foster parents. Although this serves as some incentive, it is still quite difficult to find foster homes for AIDS children because of the unique problems associated with the care of these children, their grim prognosis and almost certain death early in life, and the fear and stigma associated with this disease.

My heart goes out to the foster mother of an AIDS baby who can no longer visit with her family because her baby is not welcome in their homes. This is a problem that cannot be solved by money, but must be solved through education. People must understand that AIDS is a disease that is not transmitted by holding a baby in one's arms, or by kissing a baby. Dr. Windom, the Assistant Secretary for Health, has a poster hanging in his office that I wish I could hang on the Committee room wall, and in every hospital in this country where an infected baby lies, with no home to go to. It is a child's crayon drawing of a small child

with his arms outstretched, saying, "I have AIDS. Please hug me. I can't make you sick."

The April 1987 Surgeon General's Workshop on Children with HIV Infection and Their Families brought together many physicians, nurses, researchers, hospital administrators, social workers, and representatives of major professional and voluntary organizations, together with Federal government representatives, to discuss what is known about pediatric AIDS and our plans and hopes for the future. The Report of that workshop, which I would like to submit for the record, has been published and disseminated widely. It contains recommendations from ten work groups which focused on a wide variety of topics ranging from natural history of the infection, treatment, and risk reduction to educational, family, and financial issues. These recommendations seem to me to provide a useful framework for meeting some of the challenges presented by HIV infection in children. They have received very favorable responses from a wide variety of public and private agencies and professional organizations.

I would like to share some of the recommendations with you today, because I think they illustrate that many who are dealing with this disease are thinking along the same lines that led you to draft your legislation.

For example, the Work Group on a Model for Health Care of Children with HIV Infection, Including Both In- and Out-Of-Hospital Care, recommended the following:

- o Initiation of efforts to simplify access to existing health, welfare, social, and financial services for HIV-infected children and their families;
- o Provision of support services so that, to the extent possible, children can be cared for by their own families and in their own homes;
- o Efforts to broaden the availability of individual foster care, which is the best alternative to care by the child's own family;
- o For those children for whom family or individual foster care is not possible, establishment of innovative community-based care alternatives;
- o In those parts of the country with little or no pediatric AIDS now, immediate initiation of plans for the future by community, government, and professional leaders in health, public health, and human services.

These and other recommendations are being given careful consideration by me and by others in the Department. You will notice for example, that the proposal that will be issued soon by the Office of Human Development Services, which I described earlier, closely parallels some of the recommendations.

Indeed, they also resemble the proposals in H.R. 3009, the legislation you are considering today. We favor supporting projects to demonstrate methods of encouraging families to serve as foster families for AIDS babies who might otherwise remain inappropriately in hospitals. Hospitals do not have the personnel or the resources necessary to provide the enrichment, love, and attention that all babies need. Even the best equipped or most financially well-heeled hospital is best suited for helping sick babies get better. It is not equipped for raising children.

We also support the training of foster care personnel and the provision of respite care. AIDS babies do have special needs, and their caregivers must understand how to help them. In addition, we need to offer these caregivers support.

Community-based homes are also important. If such homes were available, babies could be cared for in an environment more conducive than a hospital to the daily nurturing attention that they need. I am convinced that no matter how hard we work, we

will always have some babies for whom home care in a family cannot be found. For these children, group homes are an acceptable alternative.

I recognize that one thrust of the legislation is to draw attention in a special way to this serious problem, and I certainly cannot disagree with that goal. At the same time, I would point out that although we support all of these proposals in concept, we believe the goals will be accomplished by programs already under way or planned within the Department. New legislation is not essential for this purpose.

Finally, we want to call to your attention that our proposal for grants to carry out much of what is contained in H.R. 3009 allocates up to \$1.2 million per year for the next three years. We believe that this is a reasonable sum, although it is substantially less than what is authorized in H.R. 3009. Clearly, we must all make decisions about where government money should be spent. This is among the very high-priority areas within the purview of this Department. Those essential activities include enormous efforts in AIDS research, service demonstration, training, education, risk reduction, and prevention for which many hundreds of millions of dollars are being spent.

In closing, Mr. Chairman, let me thank you again for your continuing interest in AIDS and your special interest in the devastating problem of pediatric AIDS. I hope that we can continue to work closely with the members of the Subcommittee to challenge this problem and this disease, and to win.

Thank you.