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FINAL REPORT

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SECRETARY'S WORK GROUP ON PEDIATRIC HIV INFECTION AND DISEASE

Department of Health and Human Services

November 18, 1988

Antonia C. Novello, M.D., M.P.H.

Chair

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Although it is impossible to mention them all by name, we would like to recognize some who contributed significant time and effort helping the Work Group understand the problems faced in confronting pediatric HIV infection and moving toward solutions.

The scientists and clinicians who offered their guidance to the NICHD at the March 1988 Pediatric AIDS Research Planning Meeting, and

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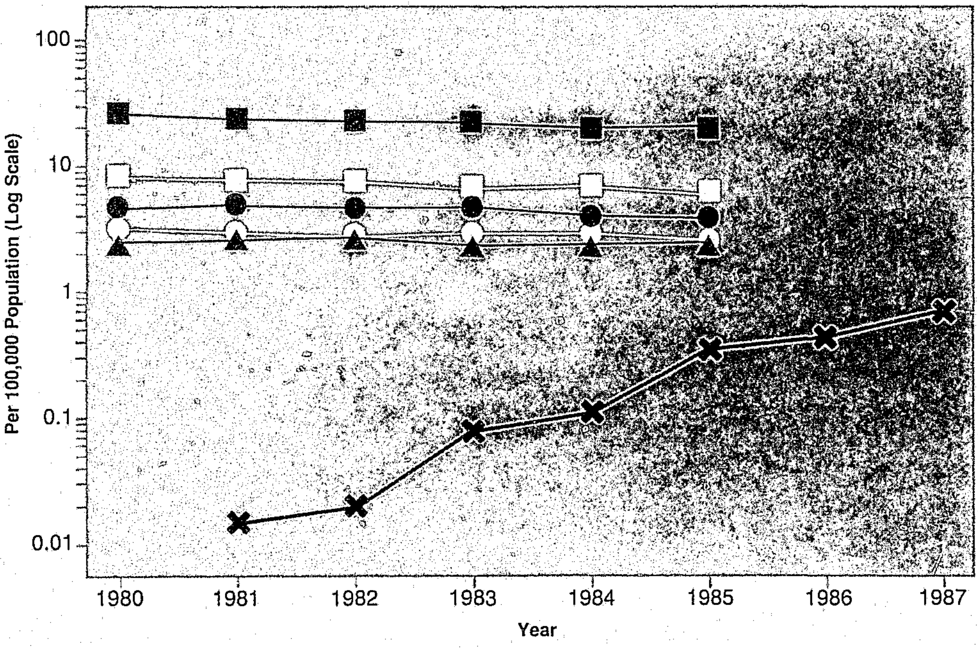
Pediatric HIV infection is a growing menace. It affects infants who acquire it perinatally from their infected mothers, children who receive contaminated blood products or blood transfusions, and adolescents who contract it through intravenous drug abuse or unsafe sexual practices.

HIV disease is rising rapidly in the ranks of the leading causes of death among children. It is already the ninth leading cause of death among children 1 to 4 years of age, and the seventh in young people between the ages of 15 and 24. If current trends continue, AIDS can be expected to move into the top five leading causes of death in the next 3 or 4 years.

CHART 5:

Five Leading Causes of Death vs. AIDS in Children One to Four Years of Age: 1980-1987



As of August 15, 1988, 70,702 cases of AIDS had been reported in the United States. Of these, 1,125 were infants and children under age 13, and 289 were adolescents 13 to 19 years of age.

These numbers, however tragic, sorely underestimate the true scope of pediatric AIDS. The official figures include only those children whose condition was reported to the Centers for Disease Control. It does not include other infected children who are either asymptomatic or symptomatic of an earlier stage of the disease. Probably for every child who meets the CDC definition of AIDS, another two to ten are infected with HIV. It is estimated that, by 1991, there will be at least 10,000 to 20,000 HIV- infected children in the United States.

In addition, the problem of HIV infection among adolescents is enormously greater than the official count suggests. In view of the lengthy latency period between infection and symptomatic disease, many of the more than 14,000 cases of AIDS reported in persons in their twenties must surely have been contracted when these people were teenagers. The repercussions of HIV infection in adolescents are magnified by the potential of these sexually active young people to become parents themselves, transmitting the virus to yet another generation. Moreover, Census Bureau statistics show that the cohort of young people currently between 11 and 24 years of age is unusually small to begin with (See Chart 17). If AIDS were to make serious inroads in this group, the long-term consequences could be disastrous for the Nation's economy (See Chart 18).

The needs of the pediatric population—infants, children, and adolescents—are incredibly complex. Having analyzed these needs and studied existing and potential ways of addressing them, the Work Group on Pediatric HIV Infection and Disease concluded that:

- Pediatric HIV infection is a complex entity distinct from HIV infection in adults, and as such requires specially tailored approaches to research, care, financing of care, and prevention;
- HIV-infected children should have easy access to care and treatment;
- Strategies must be developed to recruit more pediatric health care workers into the field;
- The Nation's adolescents are the key population to which attention and resources must be targeted;
- If an impact is to be made in the lowering of the incidence of pediatric HIV infection, early prevention efforts must be targeted to women and men of reproductive age.

The Final Report of the Secretary's Work Group on Pediatric Infection and Disease discusses these in detail, and offers recommendations for addressing them.

WORK GROUP RECOMMENDATIONS FOR IMMEDIATE ACTION:

1. A group of experts should be assembled to explore the possible benefits of a National Review Board whose function would be to review high priority or particularly novel therapeutic approaches, so as to hasten their clinical application to all levels of the population at risk. (Research: Issue 4)
2. A group of nationally recognized experts, including representatives from Human Development Services and child welfare agencies and organizations, should be convened to develop guidelines governing the participation of foster care children in anti-HIV investigational treatment programs. (Research: Issue 5)
3. The Centers for Disease Control (CDC) should convene a committee of expert consultants to discuss the need for expanding surveillance of HIV infection in children and adolescents and broadening the HIV classification system. This group should include representatives from State and local health departments who should help the group explore

the practical implications of such an expansion. (Research: Issue 6)

4. The Secretary should encourage DHHS agencies to work collaboratively with States and community agencies to support the development of family-centered, community-based, coordinated systems of care for children with HIV infection. (Care: Issue 1)

5. Up-to-date information on HIV-related counseling and other essential HIV-related services should be distributed to all organizations and individuals who are likely to be in contact with at-risk youth—hostel directors and soup kitchen personnel as well as STD workers, staff of family planning clinics, school nurses, and others. (Care: Issue 2)

6. The Office of Human Development Services (OHDS) should encourage States and localities to explore every possible option and strategy for recruiting foster parents for HIV-infected children. (Care: Issue 3)

7. The Department should develop mechanisms to encourage enrollment of all eligible children and women with HIV infection into the Medicaid program. (Financing: Issue 1)

8. The Department should facilitate strategic planning for the care of children with HIV infection by having each operating division maximize its effort to produce data on: The number of persons eligible for Medicaid but not enrolled; the number of eligible children and adults who are infected with HIV but not symptomatic; the rate at which infection is occurring among Medicaid eligible children and adults. (Financing: Issue 1)

9. The Department should encourage all States to maximize their use of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program for providing services to eligible children with HIV infection. (Financing: Issue 2)

10. The Health Care Financing Administration and the Public Health Service should work with appropriate State officials to help design optimal care packages needed for pediatric HIV cases. (Financing: Issue 2)

11. Special education and prevention programs in settings other than schools must be developed for hard-to-reach adolescents, including minorities, drug abusers, runaways, and others. (Prevention: Issue 1)

12. All Federally funded STD, family planning (Title X), or other medical clinics should be required to offer HIV counseling and testing to all women, with special outreach efforts to women of child bearing ages at risk for HIV infection. (Prevention: Issue 3)

13. An intradepartmental pediatric work group should be established (or the Secretary's Pediatric Work Group should be continued) to assure continued coordination and information exchange within the Department. (Prevention: Issue 6)

BACKGROUND

In February 1988, Otis R. Bowen, M.D., Secretary of the Department of Health and Human Services, established the Special Initiative on Pediatric HIV Disease.

1. The Purpose and Scope

The Initiative was designed to provide a focus for departmental activities dealing with pediatric AIDS and to serve as a vehicle for coordinating these activities, thereby ensuring the best possible use of Federal resources on behalf of children and adolescents with HIV infection and/or at high risk for infection.

The Initiative was established in recognition of these facts: HIV disease is gaining momentum as a threat to the lives of our children and young people; pediatric HIV disease is different from the disease in adults, both medically and socially; as a consequence, a separate pediatric agenda must be developed to deal with it. Further, the poverty, alienation, and general fragility found so often in the families of HIV-infected children called for collaborative attention from all operating divisions of the Department.

2. The Composition and Charge

To activate a collaborative, intradepartmental response to the profound and far-reaching needs of HIV families, a cross-cutting Work Group was created as the central component of the Initiative. Chaired by Dr. Antonia C. Novello, Deputy Director of the National Institute of Child Health and Human Development, the Work Group included representatives from all major elements of the Department: the Office of the Secretary, the Family Support Administration, the Office of Human Development Services, the Health Care Financing Administration, and the Social Security Administration, as well as the Public Health Service.

The overriding goal of the Work Group was to determine how the Department could respond most appropriately and effectively to the challenge of children with HIV disease. In pursuit of this goal, the Work Group was charged to undertake the following tasks:

- Provide a focus for this issue in the Department.
- Determine the steps and elements needed to develop and implement a coordinated pediatric research and demonstration agenda.
- Identify any unnecessary barriers impeding the provision of services to children with HIV infection and disease.
- Identify the technical assistance needs of local communities and groups that are attempting to deal with the incursion of pediatric HIV infection.
- Determine whether more effective prevention strategies might be pursued.

Early in their deliberations, members of the Work Group agreed that they should extend their exploration beyond infants and children to encompass adolescent, maternal, and whole-family issues associated with HIV infection and disease.

3. Approaches and Activities

The activities of the Work Group included a series of plenary meetings and subgroup sessions. At the plenary Work Group meetings, held biweekly from February through July 1988, representatives from the various DHHS operating divisions, assisted by staff and advised by visiting experts, undertook the preliminary analyses needed to proceed with their charge. Specifically, they reviewed and defined the population at risk, current research and treatment modalities, potential gaps and overlaps in research and treatment efforts, and the availability and adequacy of benefits and services for young people, infants, children, and families struggling to cope with HIV infection and its many consequences.

In this context, Work Group members also acted as a microcosm for the Department, identifying the resources their divisions were applying or might apply to the pediatric problem and also enumerating the barriers that had impeded or might impede the effective mobilization of these resources. Through their interaction and with leadership from the Chair, members were able to identify new possibilities for bypassing or eliminating some longstanding obstacles to progress.

Early in the genesis of the Work Group, four subgroups were formed to undertake more detailed analyses of the problem and to identify opportunities for innovative or enhanced Federal interventions. The subgroups focused on requirements for addressing pediatric HIV disease in the following key areas: research approaches and resources; treatment and care of at-risk, infected, and symptomatic infants, children, young people, and their families; financing of care; and primary prevention.

The organization of the report reflects the focus on the four mandates to the work group by the Secretary, as they encompass the problem of pediatric HIV infection: research, care, financing of care, and prevention. After the introduction and scope of the problem statement, the report starts with detailed discussions of the various issues addressed by the Work Group following the sequence of the four mandates and including specific recommendations pertaining to each issue discussed. Based on the detailed discussion and recommendations, the report presents a total of 47 recommendations: 13 recommendations for possible immediate action by the Secretary; 16 recommendations requiring further study by the Department; and 18 recommendations for consideration by the States. Each recommendation identifies its source in the issues section of the report for reference to the detailed discussion of the various issues.

INTRODUCTION

THE SCOPE OF THE PROBLEM

Pediatric HIV infection is a growing menace. It affects infants who acquire it perinatally from their infected mothers, children who receive contaminated blood products or blood transfusions, and adolescents who contract it through intravenous drug abuse or unsafe sexual practices.

Unheard of before 1981, pediatric AIDS is rising rapidly in the ranks of the leading causes of death among children. (See Charts 1 - 12) It is already the ninth leading cause of death among children 1 to 4 years of age, and the seventh in young people between the ages of 15 and 24. In the latter age group, AIDS deaths have increased 100-fold between 1981 and 1987.

CHART 2:

Sixth Through Tenth Leading Causes of Death vs. AIDS in Persons Fifteen to Twenty-Four Years of Age: 1980-1987

■ Congenital Anomalies

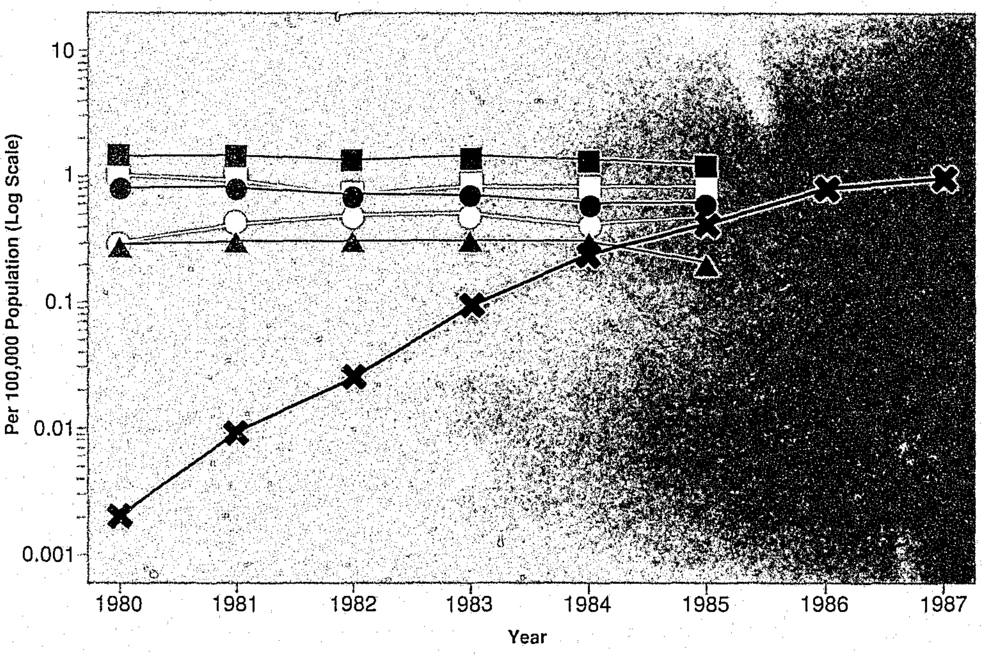
● Pneumonia and Influenza

☐ Cerebrovascular Disease

○ COPD and Allied Conditions

▲ Anemias

✖ AIDS



If current trends continue, AIDS could well be among the top five causes of death for children ages one to four in the next 3 to 4 years. Nonetheless, the official listing of the leading causes of death among children has not yet been changed to take AIDS into account.

As of August 15, 1988, 70,702 cases of AIDS had been reported in the United States. Of these, 1,125 were infants and children under age 13, and 289 were adolescents 13 to 19 years of age. More than half of those under 13 (643) had died.

These numbers, however tragic, sorely underestimate the true scope of pediatric AIDS. The official figures include only those children whose condition was reported to the Centers for Disease Control. It does not include other infected children who are either asymptomatic or symptomatic of an earlier stage of disease. Probably for every child who meets the CDC definition of AIDS, another two to ten are infected with HIV. It is estimated that, by 1991, there will be at least 10,000 to 20,000 HIV- infected children in the United States, and one of every ten pediatric hospital beds will be occupied by a child with AIDS.

In addition, the problem of HIV infection among adolescents is enormously greater than the official count suggests. In view of the lengthy latency period between infection and disease, many of the more than 14,000 cases of AIDS reported in people in their twenties must surely have been contracted when these people were teenagers. Early in the epidemic, most school-age children diagnosed with AIDS were youngsters with hemophilia; today, most adolescents are infected through sexual contact or IV drug abuse.

The repercussions of HIV infection in adolescents are magnified by the potential of these sexually active young people to become parents themselves, transmitting the virus to yet another generation. Moreover, Census Bureau statistics show that the cohort of young people currently between 11 and 24 years of age is unusually small to begin with (See Chart 17). If AIDS were to make serious inroads in this group, the long-term consequences could be disastrous for the Nation's economy. (See Chart 18)

Pediatric AIDS differs from AIDS in adults in several important respects. In infants the disease often produces severe bacterial infections and lung infections not seen in adults, with many of the children developing severe loss of developmental milestones with concomitant mental and/or motor retardation. Diagnosis is hampered by the fact that children born to infected mothers can test positive for antibodies acquired from their mothers for as long as 15 months, although just a portion of them (current estimates range from 20 percent to 60 percent) will go on to develop the disease.

Pediatric AIDS takes a particularly severe toll on minority children. Black children constitute 15 percent of the Nation's children but 53 percent of all childhood AIDS cases; Hispanic children, who represent 10 percent of the population of U.S. children, account for 22 percent of all childhood AIDS cases. More than half of the adolescents with AIDS are also of minority origin.

More than three-fourths of all children with AIDS have a parent with, or at risk for, HIV infection; however, we still cannot tell when most of them have contracted it — pre-, intra-, or post-natally — from their infected mothers.

More than half of the women infected with HIV have a history of drug abuse; close to a third have been infected through sexual contact with HIV- infected men— IV drug abusers, bisexual men, or men with hemophilia. (See Chart 15) Importantly, the vast majority of women with AIDS are in their peak childbearing years, with 79 percent between the ages of 13 and 39.

Thus most children with HIV infection are born into families facing innumerable problems—poverty, fragmentation, drug abuse, HIV infection—and often unable to care for a child with a devastating illness. As a result these children and their families have a tremendous need for public services such as health care, foster care, and income maintenance.

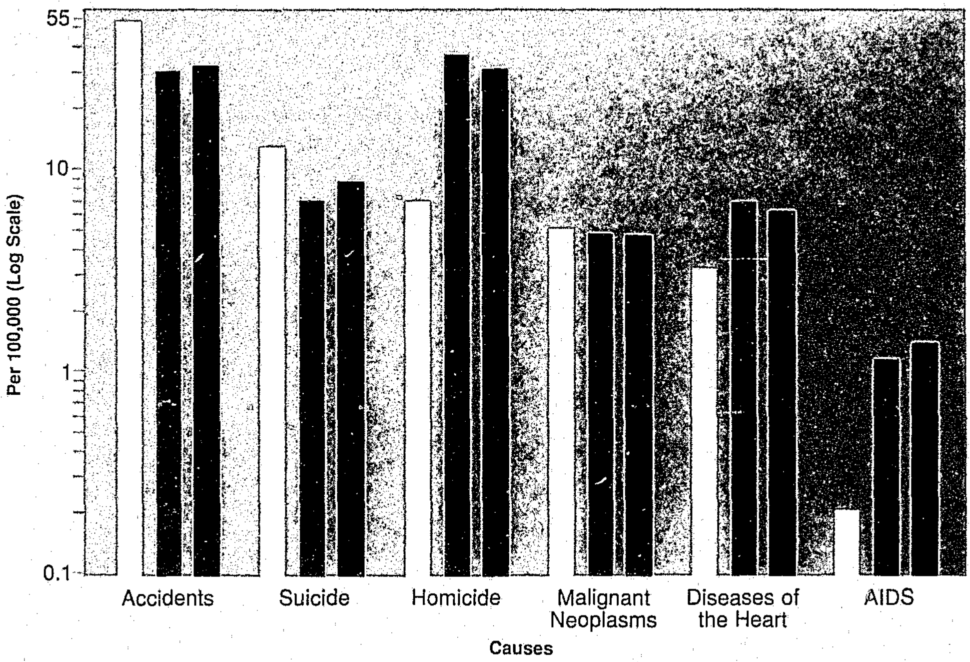
CHART 9:

Five Leading Causes of Death vs. AIDS Deaths, by Race in Persons Fifteen to Twenty-Four Years of Age: 1985

☐ White

■ Black

▨ All Others



Various therapies appear promising for symptomatic children, although few have been rigorously evaluated. Because children develop certain syndromes that adults do not, treatment regimens for children cannot be extrapolated from the experience with adults. Care for the infected but asymptomatic child has yet to be defined.

In some metropolitan areas where drug abuse is common, the incidence of pediatric AIDS cases is much higher than the national average, and the problem has reached crisis proportions. In other locales it is still an unusual occurrence. Consequently, a uniform response to pediatric AIDS in communities across the United States is not likely. Rather, programs must be tailored to fit local circumstances.

Primary prevention of HIV in infants and children involves addressing adult behaviors. But the adults (and adolescents of reproductive capacity) who are at risk of transmitting HIV infection to their children—for the most part intravenous drug abusers and their sexual partners—are among the hardest groups to reach and the most resistant to behavioral change.

Similarly, HIV infection in adolescents is fraught with problems. Not only is this population drawn to high-risk behaviors, including unprotected sexual contact and

IV drug abuse, but many adolescents are also outside the mainstream of the health care system. Like younger children, adolescents may be dependent on public systems of care; unlike younger children, adolescents often do not have a parent or other adult who will take responsibility for seeing that they obtain medical attention.

Prevention programs targeted to adolescents are currently fragmented among different agencies, and the messages they send—abstinence, monogamy, and safe sex—are difficult to present convincingly in the current atmosphere of societal permissiveness toward sexual behavior and drug abuse. Added to all these problems is a lack of research on adolescent sexuality and how to motivate them to change unhealthy behaviors.

In short, the needs of the pediatric population—infants, children, and adolescents—are incredibly complex. The Secretary's Special Initiative on Pediatric HIV Disease attempts to bring a Department-wide perspective to bear on these grave and urgent matters.

PEDIATRIC HIV INFECTION AND DISEASE: RESEARCH

Both biologically and sociodemographically, HIV infection and disease seen in U.S. children differ from the infection and disease seen in U.S. adults. Specifically, the pediatric form of this disease differs in routes of acquisition and transmission, clinical manifestations, laboratory abnormalities, and prognosis. Therefore, research, treatment, and care programs that are aimed at the adult disease and only peripherally address maternal and pediatric issues will inevitably fail to respond adequately to the emerging epidemic in the pediatric population.

Given these circumstances, it is clear that certain research goals, methods, programs, and activities must be targeted specifically to the pediatric population. The major research needs in pediatric HIV disease are: (1) ascertaining the number of infected children; (2) determining routes and timing of transmission; (3) developing accurate methods of early diagnosis; (4) identifying the full range of clinical manifestations and pathogenic mechanisms; and (5) developing effective treatment modalities. These challenges call for expanded research in a range of scientific areas including virology, immunology, molecular biology, pharmacology, cell biology, epidemiology, and the behavioral and social sciences.

Unfortunately, serious barriers impede the development and implementation of a research agenda for pediatric HIV infection and disease. Some of these barriers are familiar to medical researchers in general and some more familiar to those investigating pediatric diseases. But other barriers arise from the nature of the HIV itself, from the primary mode of pediatric transmission, and from the uniformly bleak sociodemographics of most affected children and their families. Research as well as treatment and prevention efforts often mean recruiting high-risk, poor, drug-using mothers and fathers. The earliest interventions would involve treatment through the mother during gestation, and secondary interventions cannot simply follow the protocols established for adults without addressing them in their role as parents of the next generation.

Because pediatric AIDS involves entire families, clinical pediatric research programs require a comprehensive and multidisciplinary approach. Medical care, treatment, research, and the provision of family services must be combined if these efforts are to be maximally effective.

Despite the challenges, research has progressed to the point that clinicians can now offer a variety of therapies to children with HIV infection. These include treatment with azidothymidine (AZT) (either at the physician's discretion or in experimental protocols at a number of centers); intravenous gamma globulin (either therapeutically or by experimental protocol at certain centers); antimicrobial therapy for various opportunistic infections; adjunctive therapies, including nutritional support (some of these children have failure-to-thrive or "wasting" syndromes); and therapies aimed at the various consequences of the disease, e.g., developmental interventions for children with developmental delay, or respiratory therapy for children experiencing the consequences of the various lung diseases associated with pediatric HIV disease.

To date, few of these therapies have been rigorously evaluated for efficacy in children. For instance, while there are clear-cut indications for using AZT in adults, indications for children are not so clear-cut. Other than antimicrobial therapy for documented infection, the precise therapies that should be applied to HIV-infected, symptomatic children remain matters for further studies.

The Work Group on Pediatric HIV Infection and Diseases concentrated on the most pronounced and troublesome barriers to progress, as they have experienced them and/or as reported by scientists in the research community. Specifically, they explored:

- The adequacy of current and projected funding for research on pediatric HIV infection and disease in light of the widely recognized need for a separate research agenda addressing infants, children, and youth.
- Strategies for attracting investigators to conduct research in pediatric HIV infection and diseases, despite the fact that these investigators may experience family and peer pressure against such a career choice.
- Approaches for promoting the quality of clinical research and ensuring the provision of comprehensive care to pediatric patient-subjects, despite the great difficulty of mounting and managing clinical trials involving children who come predominantly from deprived, unstable families and require unusual levels of social as well as medical support.
- Strategies for rapidly implementing effective new therapies.
- Strategies for ensuring that all children, including those who are wards of the State, have equal access to investigational treatment programs, despite previous reluctance to permit these children to participate in research protocols.
- Advantages and disadvantages of broadening national surveillance to include all children with HIV-related diagnoses.

ISSUE ONE:

Is current and projected funding for research on pediatric HIV infection and disease adequate? Should these pediatric research funds be earmarked?

To date, the reported number of children with HIV disease is 1,125 under 13 years of age and 289 from 13 to 19 years of age, a small number when compared to prevalence of the disease in the adult population. The percentage of research monies targeted to this population has been limited (approximately 4 percent of the Department's fiscal year 1987 budget for AIDS and about 6 percent of both the fiscal year 1988 and fiscal year 1989 budgets). (See Table 3).

It is well known that research conducted with children tends to be more costly than research in adults. Recruitment of children for research as well as caring for pregnant women, infants, and children who participate in research protocols involve a host of labor-, personnel-, and cost-intensive activities. It is obvious that, as the number of HIV-infected children increases, the need for research support specifically targeted to this population will become critical.

The current process by which agencies support research, i.e., the grant application and peer review system, has served the research community well. However, in a situation of such urgency as AIDS research, it would be desirable to establish a small grant program that would enable all AIDS researchers to propose, and agencies to fund, quick-turnaround, short (6-month) studies to test research ideas and therapeutic modalities in a preliminary way. This would make it possible to eliminate unworkable, invalid ideas and approaches before large amounts of money and time are devoted to them. It would also help in the early identification of projects worthy of further development.

RECOMMENDATIONS

1. The Department should support substantial increases in funding for all aspects of pediatric and maternal HIV disease research. This funding should be discernible as a separate item in departmental budgets. Funding should be targeted to specific issues (e.g., early diagnosis, surveillance to quantify the number of infected newborns, and timing of HIV transmission— whether before or during pregnancy or after delivery).

2. The Department should foster the development and funding of small, short-term grants or contracts for feasibility projects that would allow the academic and small business research communities to design and test innovative ideas. This would be a cost-effective way to evaluate ideas and therapeutic interventions in a timely fashion and to maximize the productivity of these groups, which have a contribution to make to the anti-AIDS effort.

ISSUE TWO:

How can more investigators be drawn into research relevant to pediatric HIV infection and disease?

The task of studying, treating, and caring for HIV-infected children is very labor-intensive. Medical research is more complex and demanding of human resources when the subjects of study are debilitated or threatened by death; the patient's full range of needs as human beings must always remain in the foreground. Attending to these needs may draw clinical researchers into intense interactions with a network of other professionals—social workers, rehabilitation specialists, clinical pharmacologists, recreation therapists, psychologists, psychiatrists, and various other sub- specialists, as well as hospital administrators, nurses, and other primary health care providers.

When the subjects of research are children with HIV infection/disease, extreme physical, emotional, and social pressures are heightened for all members of the research/treatment care team. In pediatric HIV-related cases, the team must confront not only the wrenching sadness of childhood pain and weakness but also the many ills that disproportionately beset these particular children—poverty, parental drug abuse, and homelessness. Dealing with these catastrophic problems requires that medical researchers interact with additional parties—with housing authorities, local school districts, public assistance programs, drug abuse treatment authorities, community health clinics, and others. Thus, it is not surprising that professional staff "burn-out" has already become a serious problem in centers treating the rising numbers of HIV-infected children.

It should be emphasized that the researchers on the team are not insulated from the emotional and social strains of pediatric HIV infection and disease. Investigators from around the country have alerted the members of the Work Group of the incredible time demands of caring for HIV-infected children who are enrolled in research programs. Reportedly, countless "research" hours are consumed by telephone calls, conferences, and numerous other interactions required to support HIV-infected children and their families.

Clearly, a host of specialists must be added to the research/treatment care team so that clinical investigators can devote themselves more fully to their particular dimension of the problem. Even with this added support, the research burden itself demands an increase in the number of investigators committed to targeted studies in pediatric HIV infection/disease.

But it will not be easy to recruit young professionals for this service. Any efforts to engage them will be set against a backdrop of fears and pressures from families, friends, and peers who may argue intensely against this area of work, as well as personal uncertainty about the wisdom of undertaking such a demanding career track. In seeking recruits, the medical research community must certainly acknowledge that participation in pediatric AIDS research does, indeed, require a significant physical and emotional commitment. In addition, entry into the field may be particularly problematic in medical centers where academic advancement is linked to achievements in laboratory research, and where clinical research may be less esteemed and less rewarded.

RECOMMENDATIONS

1. The Department should foster the development of programs to recruit, train, and retain both junior and senior level clinicians, investigators, and health care specialists who would focus their efforts on the care and treatment of pediatric HIV patients.

Such training programs should be multidisciplinary and offer experience in epidemiology, drug development, infectious diseases, pharmacology, study design, research management, data analysis (including biostatistics), and allied sub-specialties. This broad training will allow pediatric clinical researchers to remain in biomedical research even after the AIDS epidemic has passed, available for other areas of research as future needs arise.

2. Incentives should be developed to encourage additional pediatric health care workers and clinical investigators to devote themselves to the care and treatment of children with HIV disease. The opportunity for limited tours of service (rotations of 2 or 3 years) in areas of the country where children with AIDS are most heavily concentrated, accompanied by possible career advancement, should be considered. The proposed Senior Biomedical Research Service for DHHS scientists might exemplify the financial-career reward approach, and the limited-tour-of- duty strategy employed by the National Health Service Corps might be a model for the rotation scheme.

ISSUE THREE:

How can we promote the quality of clinical research in pediatric HIV infection?

Federal officials can foster advances in the care, treatment, and prevention of pediatric HIV disease by increasing support for investigator- initiated research proposals and by supporting the development of a comprehensive system for identifying research priorities and directives at the national level. The Federal research community is already striving to facilitate the transfer of knowledge gained at the bench to clinical research; the goal is to ensure that clinical trials can rapidly assess the most promising new agents. This Federal role in medical research has gained great urgency in the epidemic environment created by HIV infection. It should now be applied and targeted to the problem of maternal and pediatric HIV infection.

Research protocols for pediatric HIV infection and disease must encompass treatment of the fetus and mother during gestation as well as treatment of the child and adolescent. Thus, HIV-related research, crucial in its own right, will define the possibilities and limitations of routine prenatal intervention. Accordingly, maximizing the quality of these investigations is a matter of great concern to all members of the medical research community.

Currently, the NIAID Pediatrics Committee of the AIDS Clinical Trials Group is charged with reviewing research concepts and proposals for the treatment of HIV infection and disease. Existing pediatric centers are equipped to carry out demanding research protocols. The centers can deliver the necessary multidisciplinary care to children with HIV disease in concert with therapy-based clinical trials. They will also be the site for all phases of clinical trials. Clearly, more pediatric facilities of this sort will soon be needed in or near areas where pediatric AIDS patients are concentrated.

Given accelerating numbers of children who have or are at risk for HIV infection/disease, many scientists and public health officials now agree that selected Pediatric AIDS Centers should also carry out early testing of promising agents in infants, children, and adolescents simultaneously with their Phase I testing in adults. These studies would concentrate on the development and/or evaluation of antiretroviral agents, antimicrobials, and immunoregulatory agents. To do this work, the Centers would need considerable experience in conducting high-quality clinical research in a comprehensive, multimodal manner. The full array of medical services and sub-specialties would be needed to evaluate the safety, tolerance, and preliminary efficacy of new agents in a multisystem manner.

But at all phases, the productivity and usefulness of HIV-related investigations depend not only on well-targeted support for research; equally important is the medical community's capacity to enroll and maintain a sufficient number of children in clinical trials. This dimension of the research—which is essential for success of the overall enterprise—must also be adequately supported. This requires providing money not only for research and researchers, but also for other facets of the multidisciplinary approach.

Because serious pediatric diseases affect not only young patients themselves but also their parents and families, leading pediatric research programs (e.g., NCI's Intramural Pediatric Oncology Program) have pioneered a multidisciplinary approach, combining patient care, treatment, and research with the provision of family services. It has been their policy to meet the social support needs of families entering treatment protocols and to use their particular needs as a springboard for education and care of the family unit. Indeed, the evaluation of this multifaceted approach to family support is itself an important target for research.

Another advanced pediatric research program, the Hemophilia Program in the Office of Maternal and Child Health in HRSA, also exemplifies this type of whole-family care. This program, like the Pediatric Oncology Program, has been recognized as a preeminent model for comprehensive care of a chronic illness. Services include medical and dental care, physical therapy, orthopedic care, psychosocial care, vocational counseling, and genetic counseling. These centers serve well over half of all hemophilia patients in the United States.

No matter how well these Hemophilia Centers approach the comprehensive care of the chronically ill, still newer approaches will be needed to deal with pediatric HIV infection. Pediatric populations infected by blood and blood products represent only a small and declining proportion of the children infected with HIV, and differ from the larger population in many ways. Social support for the other cohort of children with HIV disease (i.e., the children of IV drug abusers) is inevitably complicated by the range of problems besetting the families of these children—e.g., marital instability, poverty, and the reality of one or both parents being themselves afflicted with AIDS. In such circumstances, tending to the child's and the family's need for day care, foster placement, and family support must become an integral part of the research program; without some stability, it is almost impossible for patients to comply with treatment regimens; as a consequence, the research outcomes will suffer.

An unusual amount of planning and coordination is required to conduct any clinical trial. To meet the increased demands of clinical trials in HIV-infected children, the planning and coordination should optimally be done by a group of scientists including pediatricians and obstetricians well versed in the performance of clinical trials, who also work within the framework of a multidisciplinary effort. Because the majority of pediatric HIV infections are perinatally transmitted, and because interruption of this infection may necessitate treatment during gestation or at birth, new collaborations between obstetrics and pediatrics are needed to improve the quality of research and to ensure the quality of care provided to pregnant women and their infants. This multidisciplinary effort should include pharmacologists, immunologists, virologists, and other members of the pediatric health care research team (nurses, social workers, psychologists, occupational and physical therapists).

RECOMMENDATIONS

1. The number of sites of the NIH-supported AIDS Clinical Trials Group should be increased so as to facilitate the evaluation of promising new agents for the treatment of HIV-infected children. These investigational treatment programs should be located in areas of the country where children with AIDS are most heavily concentrated.

2. Existing comprehensive care centers, such as HRSA's Hemophilia Centers, should consider extending their range of care to other children with HIV disease.

3. Because provision of comprehensive medical and psychosocial care is integral to the successful completion of investigational treatment programs for HIV-infected children, existing mechanisms for coordination and collaboration between service and research programs should be strengthened and new alliances formed.

4. Existing alliances between obstetrics and pediatrics should be strengthened and new alliances forged to advance research directed toward interruption or diminution of perinatal transmission and toward treatment of HIV-infected pregnant women at different stages of gestation, as well as treatment of the HIV-infected neonate. This might be accomplished through appropriate interagency and/or through other grant or contract mechanisms that foster interdisciplinary research.

ISSUE FOUR:

How can we make new treatments rapidly and safely available to children with HIV infection and disease?

Experience suggests that untreated HIV infection is eventually fatal in all affected individuals, both adults and children. This likelihood lends to clinical and laboratory research a sense of great urgency. Because pediatric HIV disease differs from adult disease, it is necessary to conduct innovative experimental research designed specifically for children. New therapeutic agents and other treatment modalities not previously used in children will require prompt evaluation.

It is also time to consider various populations of children as candidates for experimental therapy. For instance, in order to prevent perinatal transmission or to start treatment as early as possible, neonates should be considered as possible subjects. Medical tradition and current FDA guidelines, which restrict testing of new agents and protocols in children until at least some safety data have been collected for adults, will have to be reconsidered, and any existing guidelines for the protection of the rights and safety of children will have to be reevaluated. Some thought should be given to early testing of promising therapies in neonates and children, sometimes even before safety data have been collected in adults.

Individual institutional review boards—which are responsible for reviewing and approving projects involving human subjects—need to be aware of the possible benefits of such new approaches. To ensure that state-of-the-art care is widely available and to maximize opportunities for cooperative clinical research, it may be desirable to develop mechanisms for promoting uniformity and timeliness in institutional review.

RECOMMENDATIONS

1. The Food and Drug Administration should consider revising its guidelines to permit early testing of promising agents in infants, children, and adolescents, simultaneously with their Phase I testing in adults.

The FDA should issue treatment IND (Investigational New Drug) applications for research on promising new agents in children in tandem with applications for similar research in adults.

2. A group of experts should be assembled to explore the possibility of establishing a National Review Board whose function would be to review high priority or particularly novel therapeutic approaches, so as to hasten their clinical application to all levels of the population at risk.

ISSUE FIVE:

How can we ensure that all children, including those who are wards of the State, have equal access to investigational treatment programs?

Protection of the rights and safety of children is of utmost importance to pediatric researchers, as it is to child welfare workers. Prompted by such concern, welfare agencies in many areas of the country have sometimes refused to allow wards of the State to participate as subjects in medical or social research when the therapy or intervention appears to be experimental. But, as pediatric researchers point out, in the context of epidemic HIV infection and disease, State policies may need to be re-evaluated. Untreated infection is invariably fatal, and experimental therapies are the only ones available at present. To deny children participation in potentially promising therapy trials is to deny them the only hope they have of improving a bleak outcome. It is also important to remember that participation in investigational treatment programs ensures that a child will receive state-of-the-art care for all symptoms and any complicating illness in addition to HIV disease, thus reducing morbidity and improving quality of life.

Nationally, patterns of participation in clinical trials by minor wards of the State vary widely. Moreover, over the years, there has been little interaction between the welfare and medical communities. With the advent of AIDS, it has become clear that an ongoing dialogue between the communities is an essential means of guaranteeing that children who are wards of the State have equal access to investigational treatment programs and concomitant state-of-the-art care.

In this context, the "locus of ultimate authority" for the child becomes a problematic barrier to smooth interactions between the child welfare agency and the clinical research team. The authority can vary: In general, if the parent has voluntarily placed the child in foster care, then the parent retains the right of approval; if the child has been taken from the parent, then the State, which has legal responsibility for the child, may seek parental approval before making any major decisions involving the child; if the parents are dead and other relatives uninvolved, then the State generally retains full responsibility for the child.

Despite these complicated issues, it is apparent that a number of steps can be taken to ensure that all children, especially those who are wards of the State, have equitable access to investigational therapeutic programs and agents.

RECOMMENDATIONS

1. States should re-evaluate their current policies and procedures to ensure that HIV-infected children who are wards of the State can participate in appropriate clinical trials and treatment, with all the protection accorded to any child.

2. A group of nationally recognized experts, including representatives from Human Development Services and child welfare agencies and organizations, should be convened to develop guidelines governing the participation of children in foster care in anti-HIV experimental treatment programs.

3. State agencies should have access to a substantive data base regarding the unique characteristics of HIV infection, the range of maladies that may be associated with pediatric HIV disease, the expected outcomes, and possible treatments, including their risks and benefits, which they could use in making informed decisions on behalf of the children in their care.

ISSUE SIX:

Should national surveillance be broadened to include all children with HIV-related diagnosis?

The established AIDS surveillance system has provided extremely useful information about groups at increased risk of infection, their demographic characteristics, the geographic spread of the epidemic, trends in disease occurrence over time, and projections for the future. However, the case definition now used for pediatric national surveillance includes only the most severe cases of pediatric HIV disease and thus underestimates the total number of children with HIV infection.

With the discovery of the etiologic agent for AIDS and with the development of specific diagnostic tests for HIV, a much broader spectrum of HIV-related illness has been described. Since a significant proportion of children with HIV-related disorders are not reportable under the current system, certain public health officials and clinicians have suggested that the surveillance be broadened to include all children with HIV-related diagnoses. A fuller reporting of the problem of pediatric HIV infection would increase support for improved health care planning.

There are other important medical and public health reasons for broadening surveillance to include all children with HIV-related diagnoses. AIDS, as currently defined by CDC, develops after a relatively long latency period of months to years. Thus, people currently diagnosed and reported with AIDS have infections that were transmitted months to years in the past. If surveillance were broadened, children would be reported much earlier in the course of their infection. This would not only allow for more timely reporting of new cases, but would also facilitate prompt assessment of intervention/prevention/ treatment programs, particularly those directed at women of childbearing age and their sexual partners.

The disadvantages of broadening surveillance, however, must also be considered. For instance, in the short-term, any radical change in the scope of surveillance for pediatric HIV infection may disrupt our ability to analyze and project trends in incidence. Moreover, since counseling and testing of pregnant women is not conducted uniformly across the country, a higher proportion of affected infants would presumably be identified and reported in areas with more comprehensive HIV testing. If surveillance is broadened, the impact of differential testing practices would need to be assessed.

Further, since surveillance is conducted by State and local health departments, and is based upon cases as reported by clinicians, changes in the scope of surveillance would require input from and approval by State and local health officials and would necessitate informing health care providers of the changes in reporting. New reporting forms would need to be developed, pilot-tested, and approved by the Council of State and Territorial Epidemiologists, other State and local organizations, and the Office of Management and Budget. Legal issues would inevitably arise and reporting laws in some States might require revision. Confidentiality issues would also need to be addressed.

Some jurisdictions report AIDS cases to CDC via computer, using the "AIDS Reporting System" (ARS) for data entry. It would be necessary to update ARS, therefore, to reflect a change in pediatric surveillance. Making the necessary changes in programming at the Federal level and disseminating these changes to the States would take several months.

Training sessions for State and local AIDS surveillance personnel would be needed to ensure effective implementation of wider surveillance and associated reporting procedures. Additional administrative and professional personnel would also be needed in many areas.

RECOMMENDATIONS

1. The Centers for Disease Control (CDC) should convene a committee of expert consultants to discuss the need for expanding surveillance of HIV infection in children and adolescents and broadening the HIV classification system. The committee should include clinicians, public health personnel, other PHS agencies, and representatives from such groups as the American Academy of Pediatrics, American College of Obstetricians and Gynecologists, and others.

This group should also include representatives from State and local health departments who should help the group explore the practical implications of expanding pediatric surveillance to include all children with HIV-related diagnoses.

Children with HIV infection present enormous and urgent challenges to health and human services systems in this country. They need extensive medical care and more: medical care fully integrated with a host of other services to meet their families' complex needs. At the same time, to discourage discrimination and further social isolation, these youngsters need to be viewed as part of the larger population of children with special health care needs.

Typically children with AIDS are cared for at home, visit an AIDS outpatient clinic once or twice a month, and require hospitalization two or three times a year. Children participating in research protocols are apt to have more frequent and more prolonged contacts with the health care system.

Because the child's mother is herself frequently ill with HIV infection and/or debilitated by drug abuse, she may be unable to provide the demanding care needed by the child—and the child's siblings, also perhaps infected with HIV. Sometimes a relative such as a grandmother steps in; often the child must be placed in a foster home. For lack of sufficient facilities in some areas where AIDS is epidemic, some children become "boarder babies" in hospitals. Some communities have also set up group homes for children with AIDS.

Any care system attempting to address the specialized medical, developmental, and psychosocial needs of families and children with HIV infection must be comprehensive and integrated. Infants and children with AIDS who are receiving comprehensive care services have a markedly reduced number of hospitalizations and appear to experience an improved quality of life. As with other children with special health care needs, widespread use of ambulatory care and community-based services by children with HIV infection is expected to reduce hospital occupancy considerably, thereby reducing costs.

One major barrier to comprehensive care is fragmentation of resources. Many families of HIV-infected children are already receiving assistance from a multiplicity of health and human service agencies. In practical terms this means visits to many different sites—methadone maintenance clinics, Medicaid agencies, prenatal clinics, pediatric care clinics, welfare offices, counseling centers, etc. Access to care is also frustrated by inadequate referrals and limited follow-up.

Providers must be made aware of and advised to take advantage of the experience of several existing Federally-sponsored, comprehensive, interdisciplinary systems of care. Prominent examples are the Pediatric Oncology Program developed by the National Cancer Institute (NCI) and the Hemophilia Programs developed by the Office of Maternal and Child Health (OMCH) of the Health Resources and Services Administration (HRSA), as well as the Developmental Disabilities Program supported jointly by the Office of Human Development Services (OHDS) and the Office of Maternal and Child Health (OMCH). These models emphasize culturally sensitive delivery of health and supportive services in outpatient and community settings, minimize time spent in hospitals, and result in lower medical costs. They also, and most importantly, recognize and support the central role of the family in the child's care.

The emerging Pediatric AIDS Centers will need to develop additional approaches to support the many extended, fragmented, fragile families they are likely to encounter. For this, they must draw on a wide variety of community resources/public health care financing programs, income maintenance programs, child welfare agencies, private and public charities, drug abuse treatment centers, maternal and child health centers, and the like. The model will need to be constantly reevaluated to accommodate the reality of family disintegration (note that HIV infection in families is unique in that the child, in many cases, will outlive the parent[s]) the extent of emotional health needs, and indications for alternative guardianships.

New and innovative approaches to intervention and coordination of services for children with HIV infection are expected to result from implementation of the new legislation creating Pediatric AIDS Health Care Demonstration Projects, supported by funds appropriated in P.L. 100-202 and administered by the OMCH. Similarly innovative approaches will be needed to meet the growing care needs of adolescents.

As members of the Work Group explored models of comprehensive care and whole-life support of children and adolescents, they focused on the following set of pressing questions:

- How can we ensure that children with AIDS and their families have access to comprehensive care?
- How can high-risk adolescents be connected with systems of care and support services?
- How can additional families be recruited to provide foster care to children with HIV infection and disease?
- How can the government, either State or Federal, encourage the certification of relatives as foster parents, entitled to the same payments and support as other foster parents?
- Will group homes be needed for children with HIV infection and what approaches should be required for their development and operation?

ISSUE ONE:

How can we ensure that children with AIDS and their families have access to comprehensive care?

Services for children with AIDS are often limited or nonexistent. Where they do exist, there is frequently a lack of coordination between the agencies and professionals—public, private, and voluntary—who potentially serve the children and their families.

Fortunately, groups and individuals attempting to address the specialized medical, developmental, and psychosocial needs of children with HIV infection can take advantage of nearly a decade of experience with Federally-sponsored, comprehensive, interdisciplinary, and cost-effective systems of care developed to serve children who have various complex, long- term service needs.

The experience with comprehensive systems has convinced increasing numbers of public program managers and private third-party payers to provide case management benefits to their subscribers, especially those with anticipated catastrophic inpatient costs. These models:

- emphasize culturally sensitive delivery of health and supportive services in outpatient and community settings;
- recognize and support the central role of the family in the child's care;
- maximize coordination and management of available public and private resources; and
- minimize time spent in hospital settings.

These models also foster joint decision-making among health and other service providers in local communities, which are essential for providing effective, coordinated care programs at the community level and invaluable at all other levels of program administration.

The value of family-centered, community-based programs for children with HIV infection remains to be fully explored. This is, in part, because new information on the prevalence of the disease in infants, children, and adolescents continues to emerge. Thus, issues critical to care must be constantly reevaluated when designing programs for children with HIV infection. These issues include:

- the reality of family disintegration and death and its implications;
- the nature and extent of emotional health, developmental and neurological impairment;
- the cultural and lifestyle differences of different minority populations; and
- indications for alternate guardianship and living arrangements.

While these and other emerging issues could require readjustment of the mix of care and services provided to children with HIV infection, available evidence indicates that key principles underlying family- centered, coordinated, community-based care allow providers to remain responsive to changing needs.

Since 1975, 25 regional Hemophilia Centers and 60 affiliates have demonstrated the benefits of providing comprehensive care for persons with low income and a chronic and costly medical condition. These include improved health status, decreased hospitalizations, decreased disability, and significantly decreased costs.

The existing network of Hemophilia Diagnostic and Treatment Programs continues to provide the framework for care of children and adolescents with hemophilia who contracted HIV infection from contaminated blood products. Their excellent infrastructure not only makes it possible to disseminate and share "best practices" for this population, they have the potential for undergirding a national network of similar programs for HIV- infected children and adolescents who are not hemophiliacs. It is recognized, however, that these and other pediatric centers need additional resources to meet the anticipated needs of the full caseload of HIV- infected children and adolescents, particularly in areas of high prevalence.

A number of other HRSA programs support development of health resources and services for populations with HIV infection, and HRSA has fostered close collaboration among them by establishing an AIDS coordinating office, the Office of the Associate Administrator for AIDS. HRSA programs include:

- Bureau of Maternal and Child Health and Resources Development (BMCHRD)—Pediatric AIDS Demonstration Grants; direct services through Title V Maternal and Child Health (MCH) block grants; MCH Special Projects of Regional and National Significance grants; HRSA AIDS Service Demonstration Grants; HRSA AIDS Education and Training Centers; AZT Emergency Fund; projects to educate health professionals about AIDS (in collaboration with the Bureau of Health Professions [BHP]).
- Bureau of Health Care Delivery and Assistance (BHCDA)—Direct services to high-risk populations through Community Health Centers.
- Bureau of Health Professions (BHP)—AIDS educational programs in health professional schools and associates; projects to close AIDS education gaps among health professionals (in collaboration with BMCHRD).

Another example of the type of existing interagency networking that can benefit children with HIV is OMCH's ongoing collaboration with the Department of Education's Office of Special Education and Rehabilitative Services and the OHDS within the Department of Health and Human Services (DHHS). This effort, which has led to the implementation of early intervention programs for disabled preschoolers under P.L. 99-457, can yield significant benefits for HIV-infected infants and toddlers, many of whom have serious developmental disabilities.

Expanding foster care, adoption, and other family-oriented alternative living options for HIV-seropositive children is another area for greater cooperation. New and innovative approaches to intervention and coordination of services for children with HIV infection are expected to result from implementation of the new legislation creating Pediatric AIDS Health Care Demonstration Projects, supported by funds appropriated in P.L. 100-202 and administered by HRSA's Office of Maternal and Child Health (OMCH).

These projects, which are intended to serve as models for other communities, emphasize the delivery of services in outpatient and community settings so as to reduce time spent in hospital environments. For example, a pediatric AIDS clinic might be coordinated with on-site day care for siblings, or a drug abuse program for mothers, or meetings with representatives from various social services. These projects will be coordinated with all other programs funded by DHHS, and stress collaboration among public, private and voluntary providers, including grass roots community organizations.

Since 1983, extensive collaboration between OMCH, HCFA, and State Children with Special Health Needs (CSHN) and Medicaid agencies has resulted in a number of highly creative and successful Medicaid home- and community-based waiver programs serving children with complex care needs. These waiver programs, in which State CSHN programs typically provide overall leadership and case management, allow States to offer a variety of services rapidly and on a transitory basis to disabled persons.

This model is especially critical for future planning on behalf of children with HIV infection. Since Medicaid already pays for traditional medical services for the vast majority of current pediatric HIV patients, the waiver program may, at State option, provide targeted case management, home health services, nursing, and other direct medical care services needed by HIV-infected persons among its regular benefits.

Only a few States—among them Connecticut, New Jersey, and New Mexico--have begun to explore the full potential of utilizing Medicaid to provide flexible combinations of health care and social and support services—such as respite care, day care, home health aide services and transportation— needed to maintain HIV-infected children outside of institutions. As HIV infection spreads to sections of the country that have not yet experienced it, health professionals and human services agencies planning for these children's future care should be encouraged to take advantage of the opportunities offered by combining Medicaid waivers with other available public and private resources.

OHDS has taken a leadership role in recognizing the special needs of children with developmental disabilities and of families faced with the risk of HIV infection. In doing so, OHDS is working with the UAF's in Boston and New York to further define the problem and help identify solutions.

RECOMMENDATIONS

1. The Secretary should encourage DHHS agencies to work collaboratively with States and community agencies to support the development of family-centered, community-based, coordinated systems of care.

2. The Bureau of Maternal and Child Health and Resources Development, through the State Block Grant Program and its discretionary grant program for pediatric AIDS, should develop national networks of pediatric AIDS case management and referral systems to coordinate care, treatment (including investigational therapies), and resources for pediatric patients. These systems could also utilize the existing network of Hemophilia Centers. These systems should use all available resources—public, private, and voluntary.

3. Federal programs supporting pediatric AIDS should be enhanced by incorporating principles of family-centered care. Families should play a central role in decision-making at all levels of policy and program development and implementation. Family-to-family support services should be encouraged, with sensitivity to the diversity of families—biological, foster, and adoptive.

4. The Federal agencies should consider targeting special efforts to address risk reduction and care for developmentally delayed individuals and other persons with mental or physical impairments, and should encourage study of the developmental and neurological impairments resulting from HIV infection in children.

5. The dissemination of materials through pertinent national clearinghouses, newsletters, and project meetings, together with the provision of names and telephone numbers of key persons in Federal agencies who can provide information, should be encouraged.

ISSUE TWO:

How can high-risk adolescents be connected with systems of care and support services?

The extent of HIV infection among adolescents demands careful monitoring. Concern has been heightened by the finding that sexually active teens experience higher rates of sexually transmitted diseases than heterosexuals of any other age group. It is most worrisome that, while AIDS cases among 13- to 19-year-olds now represent only a small percentage of total cases reported, the incidence of the disease is accelerating among young adults 20 to 24 years of age. (See Charts 13 and 14).

Early in the HIV epidemic, most school-aged children diagnosed with AIDS were youngsters with hemophilia. Development of an effective blood screening program since then has limited the risk of transmission to this population via blood or blood products. Currently, for adolescents with hemophilia as for other adolescents, the major risks for contracting AIDS are through sexual contact or IV drug abuse.

Transmission of HIV among teens and young adults is expected to continue on an accelerating trend. Although educational efforts have been extremely successful in curtailing transmission among some at-risk groups, certain traits identified with adolescents (a sense of personal invulnerability, a propensity for risk-seeking and risk-taking) may ultimately undermine educational efforts directed at them. Unfortunately, unlike homosexuals or teens with hemophilia, most teens and young adults at risk are not likely to be enrolled in established systems of care. Many teens who engage in prostitution, sexual promiscuity, and IV drug abuse are also likely to be runaways and thus extremely difficult to reach for any purpose.

It is no easy matter to develop basic health care programs for the young adult, to say nothing of the emotional, health and social services they may need to arrive at responsible adulthood. Issues of consent, confidentiality, and financing of care complicate the task. Laws that prohibit medical treatment of minors without parental consent may conflict directly with guarantees of confidentiality, hindering the would-be service provider. In addition, varying patterns of public and private health insurance coverage for older adolescents can make financing extremely problematic.

This is not to say that nothing has been tried or accomplished in the arena of adolescent health education and health care services. School- based health care programs have been established in some major metropolitan districts to provide a range of services to teenagers at high risk of unwed pregnancy, sexually transmitted diseases, and various other disorders.

Already there are strong indications that indigenous outreach workers, often former drug abusers themselves, have been highly effective in conveying messages about the dangers of needle-sharing to intravenous drug abusers, adolescents and young people among them. In New York, California, and New Jersey, a variation of this peer-counseling strategy has succeeded in bringing young IV drug abusers at risk for HIV infection into treatment. The Hemophilia Centers are also addressing the problem of hard-to-reach populations at risk for HIV. The centers are currently participating in case-finding and outreach efforts, addressing culturally diverse populations.

But clearly much more needs to be done to connect adolescents with regular sources of care. It is crucial that those carrying the HIV virus be identified and provided access to treatment and comprehensive care, including intensive counseling and support services.

RECOMMENDATIONS

1. Up-to-date information on HIV-related counseling and other essential HIV-related services should be distributed to all organizations and individuals who are likely to be in contact with at-risk youth—hostel directors and soup kitchen personnel as well as STD workers, staff of family planning clinics, school nurses, drug abuse treatment centers, and others.

2. Comprehensive, coordinated, community-based systems of care must include the adolescent population. Culturally and developmentally sensitive programs must be set up to demonstrate innovative methods for reaching and caring for the adolescent population. Creative methods that would bring IV drug abusers into treatment, such as peer counseling (with ex-drug abusers as outreach workers), need to be more widely implemented.

3. Communities planning services for HIV-infected adolescents should consider exploring collaboration with the Comprehensive Hemophilia Diagnostic and Treatment Centers, to avoid duplication of effort and funds and to identify common concerns.

4. Task forces or working groups need to be formed at all levels to address important issues. They should represent a broad base of people within the community, including adolescents themselves, parents, youth-serving organizations, and grassroots coalitions.

5. Community-based programs designed for high-risk adolescents should be encouraged and helped to incorporate any strategy that shows promise for bringing young, often homeless, minority IV drug abusers into treatment or, at a minimum, for modifying their needle-sharing behaviors.

6. It is critical that innovative drug counseling programs as well as other programs for high-risk adolescents draw on local community resources and grassroots organizations to achieve their goals. Counseling and community support programs should recognize patterns of social behavior, deal with decisions about pregnancy and about HIV testing, provide crisis services, and follow up with infected adolescents and sexual partners. Effective systems are especially crucial following formal drug treatment to help recovering and former drug abusers to remain drug-free.

ISSUE THREE:

How can more families be recruited to foster children with HIV infection and disease?

The entry of children with HIV infection into foster care will surely burden an already overloaded system and compound the perennial lack of available foster parents. Specifically, child welfare experts have identified the following impediments—none of them surprising—to the recruitment of foster parents for these new "special needs" children:

- Foster parents may experience disapproval and/or rejection by friends and relatives who fear HIV infection and disease.

- Although the medical profession has developed some treatments for HIV-infected children, foster parents still need to cope with chronic illness and the eventual death of the child with AIDS.
- Some communities lack provision for respite care to ease the burden for foster parents.

In the view of some child welfare advocates, intensive recruitment efforts for HIV infected children are necessary. In the long run, the entire foster care network may benefit from such efforts. If new foster families have a generally satisfying experience with HIV-infected children, they may agree to foster other children as well.

Recognizing the importance of foster care for HIV-infected children, a number of States and localities have experimented with strategies aimed at overcoming impediments to recruitment. Some have chosen to increase maintenance payments to foster parents of HIV-infected children, reasoning that foster parents need additional support and services to handle the emotional and financial burdens of caring for a child with HIV infection. These include maintenance payments to arrange essential support and services for themselves and their foster child when subsidized, community- based services (e.g., respite care, transportation, and medical training) are unavailable, inadequate, or inaccessible. Such maintenance supplements are not offered as "hazard pay" but instead as currency to buy the support and services that may be lacking in both public and private sectors.

In other instances, a State may use the HIV crisis as a springboard for enriching the array of community-based services available to foster parents. For instance:

- States may use Federal funds to recruit foster parents and develop support services for children with HIV infection and their families. Under Title IV-E of the Social Security Act, States are reimbursed for both maintenance and administrative costs of foster care. Under Title IV-B, States receive formula grants for child welfare services, which may also be used to recruit parents.
- Additionally, States may use Title XX Social Services Block Grant (SSBG) monies to provide support services for foster parents. Under the SSBG program, formula grants are made to States and other eligible jurisdictions; within the specific limitations of the law, they are free to determine what services will be provided, who will be eligible for these services, and how funds will be distributed within the State.

However, neither maintenance supplements nor in-kind support alone can eliminate the difficulty of recruiting and retaining foster parents for HIV-infected children. Some of the reasons for the reluctance of some to foster an HIV-infected child cannot be addressed or answered through monetary support. The unjustified fears that potential foster parents may harbor, heightened by negative responses from friends and relatives, can be addressed only by increased education and counseling. Thus, the recruitment and retention of foster parents might be greatly facilitated if they could receive necessary education and counseling as well as maintenance supplements and in-kind support.

RECOMMENDATIONS

1. OHDS should encourage States and localities to explore every possible option and strategy for recruiting foster parents for HIV-infected children. In all instances, efforts should be made to contact networks of medical and nursing professionals, relatives and friends of parents who are currently fostering HIV-infected children, and existing foster parent groups. Recruitment of disabled, single, and elderly individuals as well as the child's relatives should be considered, when these individuals can be appropriately certified.

2. OHDS should take a leadership role in identifying successful models for recruiting and retaining foster parents, and begin a campaign of a selected model program. Information about these models should be disseminated to those in the field and in communities who are best able to translate model programs into practice. The National AIDS Information Clearinghouse, scheduled program reviews with the States, meetings with State and local service providers, grants monitoring activities, and ongoing communications with national professional or membership organizations, could be considered as potential means for disseminating the model idea to the communities in need.

3. The Public Health Service should publicize findings from studies of household contact of persons with HIV infection to inform the public and increase general understanding of HIV as a non-infectious agent in the household setting. By allaying fears, this should help increase the number of potential foster parents.

ISSUE FOUR:

What posture should DHHS encourage toward group homes for HIV-infected children?

Titles IV-B and IV-E of the Social Security Act, as amended by Public Law 96-272, outline the case review systems to be incorporated by State foster care programs. The overriding goal of these provisions is placement of children in the least restrictive, most nurturing and family-like environment available, preferably in proximity to the parents' home, and consistent with the best interests and special needs of the child. P.L. 96-272 makes it clear that child welfare agencies should actively seek to place children in family homes rather than group or institutional settings. Family home placement is advisable for HIV-infected children for a number of reasons:

- More than half of the newborns who test seropositive may not go on to develop HIV-infection (because the seropositivity reflects maternal infection) and can be expected to survive to adulthood. These children need a normal family environment to avoid developmental and behavioral problems that result from early isolation, abandonment, and stigmatization.

- The Centers for Disease Control advises against group settings for HIV-infected children under the age of 3, because children of that age are highly susceptible to opportunistic infections.
- The cost of group home care is often significantly higher than the cost of family care and associated support services.

Nonetheless, an influx of HIV-infected children into a resource-scarce system has prompted some States and localities to place children in group homes and residential facilities. In areas with an extraordinarily high incidence of HIV infection and a shortage of foster families able or willing to take in such children, group homes may become the only available option for their placement and care.

Leaders in child welfare warn that development of congregate care facilities should not be driven by the commercial spirit of entrepreneurs. Instead, these facilities should be carefully planned by people close to existing systems of care who understand the value of family-centered placement, but recognize the necessity for alternatives.

In this context, St. Claire's, serving Newark, New Jersey, is often cited as a model. One of the first group homes for pediatric AIDS patients, it serves as a transitional placement between hospital and family. It houses no more than five children at any time, and for no more than 20 days.

RECOMMENDATIONS

1. States should confront the possibility that congregate care may be needed at some time for some HIV-infected children. In preparation for this contingency, State and local welfare officials should be encouraged to join with corresponding health authorities to explore promising models for congregate care of HIV-infected children.
2. States should not diminish their efforts to find family placements for HIV-infected children, and they should encourage the planning of congregate care facilities only as intermediate stops on the way to family placement. Federal officials are urged to endorse this view through program letters, grant reviews, and child welfare forums.

ISSUE FIVE:

How can the Federal government encourage certification of relatives as foster parents, who would be entitled to the same payments and support as other foster parents?

The authority for certifying and licensing foster parents rests with the States, who in turn may delegate this authority to appropriate public agencies. Despite a dearth of foster parents, especially for HIV-infected children, many agencies continue to argue against kinship foster care, often on grounds such as:

- A relative is not always the best foster parent available, so placement with the relative may not be in the best interest of the child.
- Relatives should neither seek nor receive pay to care for their own "flesh and blood."

Agencies that maintain a policy against certifying and/or paying relatives as foster parents cannot easily change their rules to accommodate a particular subpopulation of relatives, i.e., relatives of HIV-infected infants. Special exceptions of this kind might expose them to charges of discrimination against the relatives of children with other special needs who were not previously included. If all children were allowed to enter a system that paid relatives for foster care, costs to the State and Federal governments might drastically increase .

The fact remains that some relatives who might provide care for an HIV-infected child are deterred by the catastrophic costs of doing so. These family members who could be potential foster parents may not know that the child is also likely to be eligible for other forms of assistance such as Medicaid, Supplemental Security Income, and community- and home- based waiver programs. A range of other community-based support services such as respite care, transportation, in-home medical services, or caregiver's training may also be available.

When relatives are not encouraged or even allowed to become foster parents, in some places serious shortages of family-based placements are likely to continue. These delays in family placement for HIV-infected children may have some serious consequences: Children remain inappropriately long in the hospitals (becoming "boarder babies"), or they are placed in group homes, or they experience multiple temporary placements, a circumstance that is probably detrimental to their long-term development.

RECOMMENDATIONS

1. States and localities should recognize relatives as an appropriate source of foster care, subject to the same review and afforded the same benefits as other foster parents. To minimize the potential financial increments that these major changes in certification and payment policies may cause, States should start to develop plans for phasing in some groups of relatives, starting with relatives of HIV-infected children, through demonstration centers.
2. State child welfare agencies should consider ways to facilitate and

accelerate the certification and licensing of potential foster parents for HIV-infected children, particularly when these individuals are relatives, but expedited action should not compromise the integrity of the foster home study and review process.

3. States should fully and affirmatively inform relatives willing to foster children with HIV infection of any financial, medical, or other support services available to them in this capacity.

4. States should be reminded that Federal fiscal participation for foster care maintenance payments under Title IV-E is provided for payments to relatives as well as non-relatives.

The universe of children ill with HIV infection comprises three distinct groups, each with different financing considerations. The largest and fastest growing is the group of infants and very young children who acquired infection perinatally. The second is a much smaller group of children infected through blood products for hemophilia and through blood transfusions. The latter are generally well integrated into the health care system. Further, due to improved safety of the Nation's blood supply, their numbers are not likely to grow. The third group consists of adolescents infected through sexual contact or IV drug abuse. Very little is known of their numbers or what kind of care they need, although data from public clinics in certain urban areas suggest that the prevalence may be quite high.

Most children who now need services for HIV disease are eligible for Medicaid or are supported by other systems of care provided at State option. However, an unknown number of "HIV families" who lack private insurance but are ineligible for public financing would be totally bankrupt in the face of associated high medical costs. Alienated youth with HIV infection or disease, for their part, are probably eligible for Medicaid by virtue of their low income, but few are enrolled. Problems of eligibility and access may become more acute as incidence of the pediatric epidemic accelerates in localities already hard-hit and as the infection extends to States that have very stringent eligibility requirements.

Further, eligibility for Medicaid does not guarantee that a child and his or her family will receive services that may be essential for them to cope with HIV disease and still remain an intact unit. Beyond the basic set of Federally mandated services, benefits vary from State to State, as do limits on reimbursement for covered services. So a similar caveat holds: as the epidemic accelerates and encroaches on previously unaffected areas, increased numbers of families are likely to suffer from discrepancies between services needed and services covered. These discrepancies are likely to worsen as research generates additional therapeutic technologies and agents that may not be allowable under current public payment programs.

Viewed from a total systems perspective, the extra burden of costs associated with the care of HIV-infected patients may appear bearable. But from the perspective of a State experiencing a large number of cases, the picture may be quite different. The Work Group recognizes local exigencies and appreciates the need to explore more far-reaching solutions with States that are particularly hard-pressed.

There are no data to determine how many children need care and cannot obtain it simply because of problems of eligibility. This is certainly the case for the children of undocumented and illegal aliens at risk of HIV. Furthermore, in any program basing eligibility on family income and resources, some will just miss the cutoff level; when they develop an injury or illness with the potential for catastrophic costs—including HIV disease—they confront disaster.

Because resource utilization appears to vary greatly from case to case and from one geographic area to another, it is possible that much can be done within the Medicaid system to make it more responsive to the needs of individuals struggling with a devastating and disruptive illness. It is important to develop a system of care that emphasizes case management for all needed health and social services, special efforts to maintain the family setting as the environment in which care is given, and the avoidance of institutionalization—especially in acute care hospitals. Current Federal financing mechanisms may be used to provide support for such system development.

The Work Group focused on the following four issues:

- What are the barriers that might prevent children ill with HIV infection from receiving care from the Department's health care financing programs?
- How can children with HIV disease be provided comprehensive health care services and ancillary support at reasonable cost?
- How can adolescents without family or personal resources gain access to publicly financed health care programs or other subsidized medical and support services?
- What financial planning resources can be made available to all families beset by pediatric HIV infection, including the working poor and middle-class as well as the categorically and medically needy?

ISSUE ONE:

What are the barriers that might prevent children with perinatally acquired HIV infection from being eligible for the full range of support available from the Department's health care financing programs?

Title XIX of the Social Security Act, or Medicaid, is our primary public vehicle for financing health care services for the poor. Since HIV-infected children are predominantly from impoverished, unstable, and/or single-parent homes and live mainly in States with relatively generous public programs, most children currently diagnosed with HIV infection are eligible for Medicaid. Very few are covered by private, third party payers.

Although the Federal government exercises some authority over Medicaid benefits and eligibility, much is left to State discretion. Consequently, States vary widely in the criteria for eligibility as well as in the benefits they offer.

By law, States are required to provide certain minimum benefits to all persons who are Medicaid-eligible. These include inpatient hospital services, outpatient hospital services, other laboratory and radiology services, and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services. Optional services include clinic services, prescribed drugs, intermediate care facility services, home health services for individuals under 21, personal care services, and hospice services. However, there is no comprehensive report detailing the needs of children with HIV and the benefit packages offered by various State Medicaid programs.

A number of avenues to Medicaid eligibility are open to children. Nationally, most children covered by Medicaid derive their eligibility from participation in the Aid to Families with Dependent Children (AFDC) program, which provides income maintenance payments to people who fall into specified income, resource, and demographic categories. The remainder of children receiving Medicaid become eligible mainly as a function of their participation in the Supplemental Security Income (SSI) program. Operated by the Social Security Administration (SSA), this program is designed to provide a minimum level of income to people who are old, blind, or disabled. Under current regulations, a child may be eligible for SSI if he/she suffers an ailment comparable in severity to an ailment that would prevent an adult from engaging in gainful activity sufficient to earn at least $300 per month.

According to the SSA, as of December 1987 application has been made on behalf of a total of 564 children under age 13 for SSI benefits, based on an AIDS or AIDS-related disability, with 90 percent receiving some form of support from the program. Medicaid data from California suggest that for AIDS and AIDS-related diagnoses, the ratio of AFDC-derived to SSI-derived eligibility for Medicaid is 5:1. From this information, it is reasonable to assume that, up to December 1987, the Medicaid program may have financed HIV- related services for as many as 3,000 children under the age of 13 years. It is important to emphasize that Medicaid is a State-Federal program, with the emphasis on "State." Thus a few basic criteria for eligibility and coverage of services are Federally required, but the great majority are an option of the State. Specifically:

- State Medicaid programs must provide coverage to all persons receiving cash assistance from the AFDC program. In addition, all Medicaid plans must cover pregnant women and children under age 5 who meet State-determined income and resource criteria for participation in AFDC—regardless of family structure and demographic characteristics. Coverage is also mandated for children in foster homes and in subsidized adoptions.
- Federal financial participation is available to targeted categories of children under age 21 and to individuals under 21 who meet the State AFDC financial requirements, but these groups are included at State option.
- States may also cover pregnant women and children under a State-defined "medically needy" category independent of any of the criteria associated with AFDC or other "feeder" programs. Thirty-two States cover a medically needy population that includes adults, children, and adolescents with AIDS. Two States have a medically needy program covering only pregnant women and children with HIV. Thirteen of the 15 States reporting the highest

numbers of AIDS cases have medically needy programs covering large groups of adults and children who would not otherwise qualify for benefits under the more stringent "categorically needy" criteria.

- A number of additional groups may be covered at the option of the State. These "poverty level groups" include pregnant women and children less than 1 year of age who have State-established incomes not exceeding 100 percent of the Federal poverty level. For a limited period, States may also make presumptive eligibility determinations for pregnant women and offer ambulatory prenatal services through specified providers while eligibility determination is proceeding. (Effective July 1, 1989, coverage to this group will be mandatory.)

At present, an unknown number of HIV-infected children remain outside the program; some of these children have no other form of insurance and come from families whose current and projected incomes would be grossly inadequate to face high medical costs. In addition, and of particular concern, is the large number of HIV-infected infants born to undocumented and illegal aliens. The issue of Medicaid eligibility in these groups will intensify when the incidence of perinatal infection increases and when the epidemic emerges extensively in States with stringent eligibility criteria. Also, as research produces more agents for treating the complications of HIV infection, we must be alert to the potential for disparities in the availability of treatment and care between those within the existing medical system and those outside of it.

RECOMMENDATIONS

1. The Department should develop mechanisms to encourage enrollment of all eligible children and women with HIV infection into the Medicaid program. These mechanisms should include Departmental grant programs that serve families with children at risk of HIV infection, including Community Health Centers, Migrant Health Centers, Maternal and Child Health Programs, and Family Planning programs.
2. States should include "medically needy" provisions under their Medicaid programs. Specifically, the Department should confirm with the States that Federal financial participation is available for these people at State option and that timely Medicaid coverage for these financially marginal groups may help control the impact of HIV in their communities.
3. The Department should facilitate strategic planning for the care of children with HIV infection by having each operating division maximize its effort to produce data on: the number of persons eligible for Medicaid but not enrolled; the number of eligible children and adults who are infected with HIV but not symptomatic; and the rate at which infection is occurring among Medicaid-eligible children and adults.

4. The Department should develop an initiative that would encourage programs that serve undocumented and illegal aliens to emphasize services to parents and children at risk of HIV infection.

ISSUE TWO:

How can comprehensive health care services to children with HIV infection be maximized within reasonable costs?

Medicaid claims data reveal that cost differences are driven mainly by differences in the utilization of long-term and inpatient care. This is true in all eligibility categories and for all diagnoses. Averages range from less than $1,000 per year for all AFDC children to $40,000 per year for disabled (SSI) children institutionalized in long-term care facilities. All groups of disabled children who do not require long-term care have Medicaid cost patterns that vary from $9,000 to $14,000 per year. In the all-AFDC-children group, ambulatory care costs account for at least one half of total costs, while in the SSI-institutionalized group, ambulatory costs often amount to less than 5 percent of the total.

In patient groups that are similar to those with HIV-infected infants, long-term care is not currently a major reason for incurred costs. When required, institutionalization generally involves acute inpatient hospital care. The perceived similarity between the comparison groups and HIV-infected children may break down, however, when and if HIV-related dementia becomes more prevalent. Important in this context is the fact that infants and very young children with AIDS consume two to three times more health care resources than others in their eligibility groups. (See Table 2).

Limited cost data for pediatric HIV disease in California show costs for children with HIV-related diagnoses averaging $20,000 per year in 986. Michigan and Florida programs report similar costs. Despite these similarities, however, the data reveal that service utilization patterns and associated costs vary greatly. Current knowledge of service utilization and cost patterns for infants and young children with HIV-related disease is obviously incomplete. What is known at this time includes:

- The costs incurred by these children appear to be similar to those of the non-institutionalized disabled population in overall service needs.
- Costs vary greatly from case to case. The cost of monitoring one baby at a New York City hospital has been cited as $600 per day, or $219,000 per year.
- High costs are directly proportional to the high utilization of inpatient hospital services.
- For the purpose of planning, a perinatally infected infant who is an active Medicaid user can be expected to cost the program from $18,000 to $42,000 per year. This estimate is derived from the $9,000 to $14,000 it costs to support a non-institutionalized disabled child times a factor of 2 to 3 to accommodate the greater expenses incurred in this type of treatment and support.

- Estimates show that by 1991 one out of ten U.S. pediatric beds may be occupied by an HIV-infected pediatric patient.

Although variations in utilization and costs for different HIV-infected infants may reflect profound differences in their conditions, it is also likely that these variations provide State Medicaid and hospital administrators an opportunity to work together to provide the most appropriate level of care for each case, with access to higher levels of care as needed. Careful consideration of current Medicaid programs along with recent Congressionally mandated expansions and waiver options could improve the quality of care available without dramatically increasing revenue needs.

There are three specific components of Medicaid that could be helpful: Case Management; Early and Periodic Screening, Diagnosis, and Treatment; and Home and Community-Based Services waiver programs.

- **Case Management.** The Consolidated Omnibus Budget Reconciliation Act of 1985, as modified by the Reconciliation Act of 1985, as modified by OBRA 1986, specifically allows case management as an optional service in State Medicaid plans. As defined in the legislation, "case management services" are intended to assist Medicaid-eligible individuals in gaining access to needed medical, social, educational, and other services.

States are permitted to limit this optional service to people with AIDS or AIDS-related conditions or with chronic mental illness. The State plan must identify the target group for case management services. Targeting may be by age, type or degree of disability, illness or condition (such as AIDS), or other identifiable characteristics.

- **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT).** All States are required to offer the Early and Periodic Screening, Diagnosis, and Treatment services as a component of Medicaid. The EPSDT program is directed toward improving the health status of children and may be made available to all Medicaid-eligible individuals under age 21. EPSDT can take the form of sets of services separately targeted to at-risk infants, children, or youth populations. Incorporating early identification and case management, EPSDT can function as the governor of a system of health services. The full EPSDT package includes not only the services themselves but an affirmative commitment by the State to institute procedures for ensuring that eligible children actually receive available preventive services, health care screening, and any necessary follow-up services.

The State may provide services in greater amounts, longer duration, and wider scope to EPSDT recipients than to others. Any mandatory or optional diagnostic or treatment service that is offered under a State's plan must be made available to EPSDT recipients who require it. Under EPSDT, States may identify additional services needed by

Medicaid-eligible pediatric HIV patients and provide them without the limits applied to other Medicaid populations. It should be noted, however, that these expanded services may not be categorically "targeted" toward individuals with particular diseases or conditions such as AIDS, but rather must be made available on the basis of medical necessity to all eligible children who require them.

The statute and regulations governing EPSDT require State Medicaid agencies to establish working relationships and networks with related agencies and programs. Coordination and collaborative efforts may be undertaken to provide outreach, screening, diagnosis, treatment, and referral services for specific population groups or geographic areas in need of special attention. Federal financial participation is available to cover the costs to public agencies of providing direct support to Medicaid agencies in administering the EPSDT program. State Medicaid agencies are required to coordinate services with Title V (Maternal and Child Health) programs, with whom they share populations and often providers, as well as a common concern for child health. Coordination with Title V and other programs should promote effective and efficient use of services and continuity of care. Relationships with schools may be useful in identifying at-risk adolescents; ties with social services can deal with transportation, referrals, and training.

- **Home and Community-Based Services (HCBS) Waiver Programs.** Currently, two HCBS programs are available for extending Medicaid eligibility to certain uncovered groups and for expanding the range of allowable services.

Under Section 1915(c) of the Social Security Act, the Secretary is authorized to grant waivers, at State request, which would allow the provision of a broad array of home and community-based services not otherwise covered with Federal financial participation. Section 1915(c) also authorizes the waiving of several other statutory provisions that would otherwise impede the development of alternative community delivery systems. In addition, the Act requires that States requesting HCBS waivers make adequate provision for client health and welfare, and for standards of provider participation. Client participation on a waiver must be entirely voluntary. Finally, States may make waiver coverage available to individuals who would be eligible for Medicaid only in an institutional setting. States may serve people with AIDS on waivers targeted specifically towards them or through waivers for persons with mental or physical impairments in general. Seven States have done so, among them New Jersey, New Mexico, Hawaii, and Ohio.

The original section 1915(e) HCBS waiver authority has existed since 1981. The Medicare Catastrophic Coverage Act of 1988 added a new Medicaid HCBS waiver authority under section 1915(e) of the Social Security Act. The new section allows

States to request waivers to provide HCBS to children infected with HIV or drug-dependent at birth. This program is targeted specifically to children under 5 years of age for whom adoption or foster care assistance is or will become available under the IV-E program.

With emphasis on alternative settings for care, case management and monitoring, and support services of various sorts, the specific provisions of the Medicaid program may prove very useful to States that are trying to accommodate the shifting medical needs of children with HIV disease.

RECOMMENDATIONS

1. The Department should encourage all States to maximize their use of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program for providing services to eligible children with HIV infection.

2. States should consider developing and utilizing Home and Community- Based Waivers. These should give special consideration to the array of services and benefits that may be needed for children with HIV infection and disease.

3. All States should develop optional case management services in cooperation with the State's Maternal and Child Health program, and ensure that these services are tailored to meet the special needs of eligible children with HIV infection and disease.

4. The Health Care Financing Administration and the Public Health Service should work with appropriate State officials to help design optimal care packages needed for pediatric HIV cases.

5. All States should consider including HIV testing, which has recently become a covered service under EPSDT, in their screening programs.

6. The Department should consider publicizing the fact that people who qualified as amnestied aliens can become eligible for Medicaid services.

7. DHHS should support a comprehensive study on the cost, financing, and quality of health care services for HIV-related conditions. Information should be developed on total national cost of the disease, variation in resource utilization by different risk groups or geographic areas, distribution of the financial burdens across payers, and the future public and private resources that will be needed as the epidemic changes.

ISSUE THREE:

How can adolescents without family or personal resources gain access to public health care financing programs and/or to subsidized medical and social support services?

Adolescents at risk of contracting HIV or already infected with the virus represent a significant unknown quantity. We have little knowledge of where they live or what their other sociodemographic characteristics might be. It is not known what proportion are homeless, runaways, or "street kids." Nor is it known how many live with intact and/or stable families. Current studies being conducted by the CDC with the Job Corps, with college student populations, and in sexually-transmitted disease (STD) clinics and family planning clinics may help answer some of these questions.

It is widely believed that adolescents who lack family and personal resources also lack access to health care services. In some States, these young people could qualify for cash assistance, Medicaid, and other public support programs. Across the country, certain well-established, publicly subsidized facilities—e.g., STD clinics, family planning clinics, and prenatal clinics—make services available free of cost or on a sliding cost scale.

However, young people in alienated circumstances are not likely to apply for public programs or to attend these free clinics, even if they know about them. Runaway hotlines, storefront outreach centers, missions, and soup kitchens may provide a better means of reaching high-risk adolescents with information on eligibility for Medicaid and other public support programs, or with medical services. Unfortunately, programs of this type are few and scattered; they are not available in numbers equal to the case management needs of the one million adolescents who run away in a given year, or for "street kids."

As HIV infection and disease increases in adolescent groups, providing young people with needed services in a timely fashion will become a critical public health challenge.

RECOMMENDATIONS

1. The Department should convene representatives from State Medicaid programs, from the Health Care Financing Administration, and from the Federal Maternal and Child Health program to plan a coordinated strategy for ensuring that publicly financed or subsidized health care services, as well as drug abuse treatment, are available to people who lack family or personal resources.
2. At a complementary forum, the Department should convene youth advocates from National, State, and grassroots organizations who could assist in devising a strategy for helping young people understand the services available to them and how to gain access to those services.

ISSUE FOUR:

How can the Department best meet the cash and subsistence needs of families with HIV infection?

Numerous studies, including the Report of the Surgeon General's Workshop on Children with HIV Disease and Their Families, have called for a case management approach to HIV treatment. In addition to a continuum of care, the case management approach provides classical medical treatment and nursing support, emotional health services and counseling, nutritional programs, day care, and housing and social services in general. A financial management counseling and referral component could be added to help families in the utilization of the continuum of care.

There are precedents to this approach, such as the programs developed for diseases such as cystic fibrosis and hemophilia. Support provided to the families in these programs has a financial management component that has been recognized as an important contribution to the effectiveness of overall therapy and whole-family support. Under this financial management component, trained specialists help families identify the financial and other supports needed to address their situation and help them contact the organizations and individuals who contribute resources for specific purposes. A wide range of institutional, voluntary, and other sources of help may be used to obtain loans, grants, private charity, public assistance, and/or access to special programs.

RECOMMENDATIONS

1. The Department should encourage State social services and welfare agencies to examine the special needs of medically impaired families and individuals, and develop improved outreach programs. Specifically, States should be encouraged to establish liaison with the proposed network of HIV treatment programs and staff (including financial management and benefits specialists) to help foster an expanded pediatric HIV case management system of care.

2. The Department should encourage the expansion of the HIV care model to include benefits specialists and/or financial advisors who can assist families in meeting their cash and subsistence needs as well as their medical needs. This approach may be piloted and disseminated through programs such as Pediatric AIDS Health Care Demonstration projects (under Public Law 100-102). Additionally, this expanded case management approach to treatment should be evaluated for its potential contribution not only to the care of pediatric cases, but also to adults.

3. The Department should encourage sensitivity and flexibility in State and local policies and procedures to facilitate the process whereby medically impaired families apply for financial and social services so that this process does not become an extra burden in itself. Specifically, States should take advantage of allowable State plan options that would further this recommendation.

Because the pediatric population spans the age groups from birth to 19, prevention must focus on HIV infection acquired: (1) perinatally, (2) sexually, and (3) through sharing of contaminated needles. Thus, the chief target audiences are women of childbearing age, and young people of both sexes who risk infection through sexual contact or drug abuse. Prevention must also address other adult populations whose behaviors result in transmission of HIV infection to pediatric populations.

As one of its first endeavors, the Work Group inventoried AIDS/HIV programs relevant to prevention currently being sponsored by DHHS agencies. It is clear that a great deal is being done by all the agencies of the Public Health Service in the area of AIDS information and education. In fiscal year 1988, PHS agencies spent over $296 million on AIDS information and education, and in fiscal year 1989 spending is expected to increase to over $373 million. Of that amount, more than $36 million will be devoted to information and education targeted to youths of school and college age. In developing these preventive efforts, the Federal government has formed partnerships with State and local governments, community-based organizations, and national organizations in the private and voluntary sectors.

As we approach the end of the first decade of the AIDS epidemic, it is apparent that HIV infection among adolescents presents special challenges. Testing and informing partners and parents of adolescents who are below the age of majority raise a special set of ethical and legal issues. Adolescents may have cognitive differences in the way they process medical information, and emotional differences in their coping styles. There are special medical, economic and social implications for teenage mothers delivering HIV-infected babies. In contrast to the homosexual adult population, adolescents lack unified community support.

Their patterns of sexual behavior are different; more are "sexual adventurers;" fewer use contraceptives. Furthermore, the drug abuse that is widespread during adolescence, including the abuse of alcohol and non-intravenous drugs such as crack, encourages risky behaviors by lowering inhibitions. (It also lowers immune system functioning. Researchers have hypothesized that a substance abuser exposed to HIV may become infected more readily than a non-abuser and, once infected, may experience a more rapid onset of symptoms and be more vulnerable to opportunistic infection.) Finally, there is an apparent lack of services and educational interventions that are perceived to be convenient, appropriate, and attractive to adolescents.

Although 13- to 19-year-olds with AIDS represent less than 1 percent of all AIDS cases, more than 20 percent of all AIDS cases have been diagnosed and reported in people between 20 and 29 years of age. Because the latency between infection and the full-blown syndrome of clinical AIDS may be 8 years or more, a significant number of those diagnosed as young adults can be assumed to have been infected during adolescence. Considering AIDS cases in young adults (20-24, 24-29) as a byproduct of behavior during adolescence (13- 19) puts the issue of adolescent HIV infection into its true perspective.

In April 1988, the House Select Committee on Children, Youth, and Families, outlined the prevention needs of adolescents in their report, *A Generation in Jeopardy: Children and AIDS.* The Select Committee found that:

- The number of AIDS cases among adolescents is currently low. However, teen sexual activity, high rates of sexually transmitted diseases, and some evidence of increasing heterosexual transmission of HIV among adolescents suggest that youths are a group particularly at risk for the development of AIDS.
- Adolescents need education that enables them to understand and avoid behaviors associated with HIV transmission, including education stressing the value of abstinence and monogamy as well as explicit information regarding the use of condoms. Despite this need, not all States have mandated such education in the public school systems.
- Prevention strategies to stem the spread of AIDS among adolescents are limited. Additionally, the adolescent's sense of invulnerability and lack of knowledge about AIDS make preventive education difficult.
- Minority teens, runaways, and other adolescent populations are especially at risk for HIV infection because of their higher prevalence of sexually transmitted diseases, combined with the multiple risks associated with poverty. Such groups urgently need AIDS education.

Figures from the National Center for Health Statistics paint a grim picture of the environment in which today's adolescent lives: Every 78 seconds, an adolescent attempts suicide; every 90 minutes, one succeeds. Every 20 minutes, an adolescent is killed in an automobile accident; every 80 minutes, an adolescent falls victim to a homicide. Every 31 seconds, an adolescent becomes pregnant. Nearly half of all high school seniors have used an illegal drug at least once, and almost 90 percent have used alcohol.

Adolescent sexual behavior is a major cause of concern in the spread of HIV infection. Although the rate of sexual activity among some adolescents has stabilized, the age of first sexual intercourse is decreasing. (A survey in Baltimore, Maryland, found that 50 percent of the black males had become sexually active before they reached the age of 13.)

Heterosexual transmission may play a greater role in HIV transmission in adolescents than in adults; during the adolescent years, the ratio of male to female AIDS cases is 7:1; in adults it is 12:1. (See Chart 15). In 1982, 45 percent of all girls ages 15 to 19 were sexually active, and some one million teenaged girls per year, or about 1 in 5, of the sexually active adolescents between 15 and 19 years of age become pregnant.

A number of adolescents have multiple sexual partners, usually via serial relationships. Nationally it has been found that, while most sexually active girls have one or two partners, 18 percent have more than three. It is also clear that the chance of acquiring HIV increases with the number of sexual partners. Data from Albert Einstein School of Medicine shows that their first six HIV-positive teenage patients had a total of 50 partners.

The "bridges"—adult IV drug abusers, adult homosexuals or bisexuals and their partners—by which the virus crosses into the adolescent population must not be forgotten. (See Chart 16). Teenagers often become involved with older partners who have numerous sexual contacts. Nor can it be discounted that some adolescents are themselves IV drug users or homosexuals or bisexuals. Moreover, homosexual/bisexual behavior or prostitution is often related to an exchange of sex for crack. Thus non-IV drug abuse presents a new and significant bridge between different populations.

The problem of sexually-transmitted diseases (STDs) among adolescents is equally worrisome. Nearly 25 percent of all reported cases of STD occur in adolescents, and the fact that about 2.5 million teenagers (1 out of every 7 teens aged 15 - 19) contract an STD each year indicates the potential for rapid transmission of diseases in this group. The rates of STDs—gonorrhea, pelvic inflammatory disease, syphilis, and chlamydia—are higher in sexually active adolescents ages 10 to 19 than in all other age groups of sexually active Americans. Data from New York's Mount Sinai Hospital clinic show that 65 percent of adolescents had anal intercourse in the previous 3 months and, of that group, 74 percent never used condoms. (Condoms were more likely to be used for vaginal intercourse.) Overall, about one-third of sexually active adolescents nationwide use no contraception, and only a small percentage of adolescents report the consistent use of condoms.

Adolescents are not only sexually active, but consider themselves invulnerable and immortal. The risks from the infectious diseases of childhood have passed, while the medical consequences of aging lie ahead. By ignoring safe sex practices, they may create a large pool of persons susceptible to HIV transmission. These facts become even more ominous when we think of these young people as the progenitors of the next generation. Adolescent sexual behavior has the potential for spreading HIV infection not only laterally but vertically as well, when this group starts to reproduce.

In this AIDS epidemic, geography can be destiny. As of now, most reported cases of AIDS in adolescents and young adults (60 percent) come from New York, New Jersey, California, Texas, and Florida. But we must recognize that U.S. adolescents of all socioeconomic conditions are geographically mobile, making it likely that the virus will spread to other communities. This must be kept in mind as we devise programs and techniques to curtail the potential spread of HIV infection in the adolescent population.

As serious as the HIV epidemic is for adolescents today and in the near future, it has the additional potential of exerting a disproportionate impact on the economic future of the Nation by the year 2010, if early prevention techniques are not immediately targeted to the adolescent population.

As data from the Census Bureau show, the 13 years between 1964 and 1977 saw a decline in fertility, with smaller birth cohorts, in contrast to the "baby boom" that immediately followed World War II. These babies are now young adults 11 to 24, and one measure of their size is that the number of 16-to 19-year-olds shrank 16 percent between 1976 and 1986. (See Chart 17).

By 2010, when these young people reach the ages of 33 to 46, a time of peak productivity, the first of the baby boomers will enter retirement. Thus the stage is set for serious economic complications: a growth in the elderly, dependent population will be unmatched by growth in the productive working-age population. (See Chart 18). A byproduct of this disparity will be a demand for women of childbearing age to remain in the workforce, further threatening the robustness of a future generation.

If we superimpose AIDS on this scenario, the prospects become grimmer still. In the absence of targeted prevention programs, today's adolescents, their ranks possibly thinned by the HIV epidemic, will become the population unable to give the Nation's economy the support it needs. Indeed, those who survive AIDS, possibly disabled by chronic illness, will add to the economic burden. To avert such a possiblity, the adolescents of today must remain healthy and productive.

The Work Group chose to concentrate on the following six areas:

- How can we best address the prevention of HIV transmission among adolescents?
- How can we address the great need for prevention activities among populations that have not been adequately reached by existing programs?
- How can we address the need for more timely counseling and testing among women of childbearing age who are at risk for HIV infection and who risk transmitting the infection to their infants?
- How can we improve our understanding of risk behavior and our ability to motivate behavior change so as to prevent transmission of HIV, especially to pediatric—including adolescent—populations?
- How can we enlist the maximum contribution from the private and volunteer sectors for

prevention of pediatric HIV infection?

- How can information about pediatric AIDS be developed and effectively transferred into practice?

ISSUE ONE:

How can we best address the prevention of HIV transmission among adolescents?

Prevention of HIV infection among adolescents presents special challenges, and the urgency of adolescent prevention programs must be made clear to the Nation. Relatively few adolescents with AIDS have been reported so far. However, HIV infection rates for both the general and the adolescent populations are still in the process of being accurately estimated, and existing knowledge regarding the drug-abusing and sexual propensities of adolescents would suggest that they are uniquely at risk.

Adolescents show a serious disregard for health and healthful behaviors. A recent survey of eighth- and ninth-graders, funded by DHHS, showed that the young people drink alcohol, use addictive drugs, eat poor diets, are subject to severe emotional stress, use firearms, and are ill-informed about serious health problems, including AIDS and STDs.

Few adolescents participate in a health care program. Some had their last contact with health care personnel when they got a vaccination "booster" before entering first grade. Most get no more than the physicals needed for sports programs or summer camps, while drop-outs and alienated youths lack even those opportunities for health care and information.

If we are to prevent further inroads of the HIV epidemic in this population, unequivocal, direct, and reinforcing messages must be conveyed to alert an entire generation of Americans who unknowingly are now at risk for contracting HIV. Achieving effective prevention for both the short and long term may be more important for this part of the population than for any other.

It is the consensus of the Work Group that, in order to reach the majority of youths, HIV prevention must be incorporated into the school curriculum. DHHS, through CDC, contributes substantial funds to school health education to prevent the spread of HIV. Many school systems have responded to the challenge, but more remains to be done.

In December 1987, the National Association of State Boards of Education surveyed State education agencies to determine the extent of AIDS education in public schools. The survey found that over a third of States formally mandate HIV instruction, while others provide HIV education in the absence of a formal mandate.

States have faced a variety of problems in implementing HIV education. These include opposition from some local communities and apathy from others, lack of funding to carry out planned projects, lack of a standardized and comprehensive health curriculum into which HIV education may be fitted, and failure to introduce HIV education early enough so that prevention messages can be learned and absorbed before the onset of sexual activity.

To provide the Nation's adolescents with the information they need to protect their health, we must reach beyond the tradition of "benign neglect" and tolerance of adolescent experimentation. To overcome the adolescents' sense of invulnerability, we must reach them early and impart clear, straightforward, and unambiguous knowledge.

One possible approach is exemplified by a Comprehensive Health and Safety Education (CHASE) Program targeted to adolescents. As envisioned by the Work Group, this would be an educational course offered by local community centers through Federal grants. Its aim would be to reduce the risk to adolescents of some of the leading causes of death in this age group—accidents, suicides, homicides, and most recently, AIDS. The program would equip adolescents with a set of skills to use when their lives or those of their peers might be in danger. CHASE instruction would also enable them to recognize and understand signs of emotional stress in themselves and others, and to become active participants in their own care and that of their peers. CHASE, as proposed, is essentially a vehicle of empowerment for adolescents to achieve a measure of control over their health behaviors.

In general, the CHASE course would emphasize the day-to-day threats to health which adolescents are exposed to and the value of eschewing willful exposure to them. In addition, unambiguous, age-, development-, and culture- appropriate information about infections such as HIV and STDs would be provided as well as knowledge of the behaviors which lead to them—needle- sharing and unprotected sex. The program should teach adolescents the concept that preventive medical care is the path to the enjoyment of good health now and in the future.

So as to reach the greatest possible numbers, this program could be presented as a prerequisite for participation in the activities adolescents value most—namely, driving a car and earning money. The latest estimates from the Bureau of the Census and the Bureau of Labor Statistics show that, of the 14.9 million adolescents between 16 and 19 years of age, 7.9 million are either employed or seeking employment. Figures from the Federal Highway Administration show that 9.9 million have a driver's license. Thus, making a work permit and/or a driver's license contingent on participation in the CHASE program would reach between 55 and 65 percent of this population.

RECOMMENDATIONS

1. AIDS education should be part of a comprehensive health and safety education program (CHASE). To develop such a program, we must make sure that collaboration among schools, health departments, and community youth programs is established. These efforts must include both family life and sex education. Such a program must be sensitive to varying cultures and lifestyles. Schools and communities must individually decide the content of the curriculum and what emphasis such a program should place on the behaviors that promote prevention of HIV infection, including deferral of sexual activity, abstinence, monogamy, and use of barrier contraceptives (condoms). In addition, this Work Group supports the position expressed by the Surgeon General's Workshop on *Children with HIV Infection and Their Families:* "We hope the program would help youths to develop a sufficient sense of themselves to postpone intercourse . . . and insist on the use of condoms when becoming sexually active."

In addition to AIDS education, the proposed CHASE program must be inclusive of all adolescent health problems, covering health maintenance, sex education, first-aid, as well as some aspects of teenage pregnancy, drug abuse, and other risk-taking behaviors. The program should also open opportunities to discuss concerns, whether emotional or sexual, without ridicule or shame. It should try to develop positive skills that will allow adolescents to deal with peer pressure, cope with stress and anger, and build self-esteem. The goal should be to teach the adolescent to be comfortable with his/her body and its function, and promote the idea that good decision-making in adolescence is a ticket to good health in adulthood.

2. Every local school board (including boards responsible for public, parochial, and private schools) should address the need for HIV education and determine, with input from parents, teachers, students themselves, community leaders, and other legitimately concerned parties, the content and timing of such HIV education in local schools. To be effective in modifying behavior, this education must be ongoing, rather than a one-time intervention, and should utilize special educational techniques that have proven to be effective in young people, e.g., peer counseling, skills training, etc.

3. State governments should consider requiring HIV education as a condition for funding at the local school level. Education continues to be essential to alert youths about the risks of drug abuse and sexual behaviors that may expose them to HIV infection.

4. Special programs in settings other than schools must be developed for hard-to-reach adolescents, including minorities, drug abusers, runaways, and others.

5. DHHS, through the CDC AIDS Clearinghouse, should develop a

collection of all relevant educational material appropriate for all ages to be disseminated by request to community groups.

6. DHHS should consider establishing a bureau of speakers that would be cognizant of state-of-the-art HIV information and available to communities for educational programs.

ISSUE TWO:

How can we address the great need for prevention activities among adolescent populations that have not been adequately reached by existing programs?

Certain groups in the U.S. population, because of their behavior or the circumstances of their lives, are at increased risk of becoming infected with HIV and of transmitting it to their newborns, and to their sexual partners. Included in these groups is a population not frequently acknowledged—the adolescents.

Ironically, these persons at highest risk are least likely to be reached by existing prevention programs. This section addresses the need for special prevention programs for these hard-to-reach populations:

1. Intravenous drug abusers
2. Minorities
3. Runaways and homeless youths, and youths out of school
4. Immigrants
5. Bisexual men
6. Persons with mental or physical disabilities
7. Pregnant teenagers

1. IV Drug Abusers

As shown in Table #1, approximately 80 percent of all perinatally-acquired HIV infections are secondary to IV drug use by an infected mother or her sexual partner(s). By sharing needles, intravenous drug abusers transmit HIV to one another; through sexual intercourse, they can transmit the infection to their heterosexual partners and, through them, to infants. This behavior is a particular threat for inner-city adolescents and "street kids."

In an attempt to control the spread of AIDS, this year PHS has requested increased funds to expand treatment slots for IV drug abusers. These funds will be channeled to localities with high rates of drug abuse and HIV infection. Interventions will range from intensive behavioral counseling and follow-up to providing information on HIV transmission and risk reduction measures for hardcore users unwilling or unable to give up drugs. Funded programs will exchange information on strategies that appear to be successful.

Projects such as these should be further evaluated and, if successful, encouraged and replicated; they should include a special focus on adolescents, as they will be important in halting the spread of pediatric AIDS at several critical points: perinatal transmission to infants, sexual transmission to teenage sexual partners of IV drug abusers, and transmission to adolescents and young adults through needle-sharing.

2. Racial and Ethnic Minorities

Of the 1,125 children with AIDS reported in the United States as of August 15, 1988, three-quarters are black or Hispanic. Black and Hispanic children also represent 85 percent of those with AIDS who have acquired HIV infection perinatally. Among the 6,219 women with AIDS reported in this country, 71 percent are also black or Hispanic. Likewise, more than 50 percent of adolescents with AIDS (between the ages of 13 and 21) are black or Hispanic. Needle-sharing by IV drug abusers plays a central role in the spread of HIV among minorities, and is directly or indirectly the most important conduit for HIV transmission to minority families and children.

Clearly, prevention of pediatric HIV disease will require targeted education and prevention programs for minority men, women, adolescents, and children. DHHS programs have made a start at targeting prevention efforts to minorities, but more remains to be done.

Minorities represent a broad range of diverse sub-populations that vary by race, ethnicity, language preference, socioeconomic status, culture, and level of education. Effective prevention strategies must take this diversity into account. Such strategies must incorporate the values of the particular group being addressed, and must attempt to strengthen existing social norms that will motivate and reinforce appropriate behavior. Specifically, in attempting to halt perinatal HIV transmission, it is important to recognize the importance of pregnancy and childbearing in some cultures.

To be most effective, strategies for HIV prevention must be targeted to the particular minority community, and be developed and implemented by members of the same group. HIV education and prevention efforts will reach the maximum number of people by involving minority community leaders, organizations, and institutions who know the values and standards of the community. Messages must be culturally specific, in the language of preference, and at an appropriate literacy level. They should be presented in multiple settings and utilize a variety of approaches. Empowerment, by allowing communities to change from within, is an essential component of any prevention strategy.

We must also realize that prevention messages may go unheeded unless other needs of those affected by HIV are addressed. HIV education and prevention activities must be linked to medical, obstetrical, and mental health services; drug abuse treatment; nutrition education; counseling; housing; job skills; and financial support.

Finally, to be effective, programs to prevent pediatric HIV infection among minorities must specially target minority men. If the minority community is to succeed in reducing pediatric HIV infection, then minority men as well as women must accept behaviors such as abstinence, monogamy, and condom use, and must reject behaviors such as intravenous drug abuse/needle sharing and unprotected sexual contact.

3. Runaways and Homeless Youths and Youths Out of School

DHHS estimates that as many as one million youngsters run away from home each year. One quarter of a million remain homeless and on the streets. Little is known about the general health status of this group. One recently published study of "street kids" visiting an outpatient medical center in Hollywood, California, found that this group, compared to non-runaways, had a wide variety of medical problems and health-compromising behaviors, including suicide and depression, prostitution, and drug abuse.

It can be assumed that runaways and street children, because of unique problems they face, are at increased risk for exposure to HIV. Homosexuals are well-represented in this group; in fact, many cite their homosexuality as the reason for leaving home. Often such youths resort to promiscuous sexual activity, whether homosexual or heterosexual, as a means of monetary support. Their lack of shelter, adult supervision, and protection puts them at increased risk of rape and other forms of sexual abuse. It follows, then, that females in this population experience more unwanted, unplanned pregnancies, while males may experience more STDs. Many runaways use intravenous drugs, share needles, and/or have sexual partners who use drugs, all of which add to their problems.

Runaway and homeless youths are a particularly difficult group to reach. Many remain on the street and never come to a shelter; some spend very little time at a shelter. Because they seldom use any of the community institutions--such as churches, schools, health centers, and social clubs—where prevention messages may be presented, these youths present a special challenge to communities determined to combat the spread of pediatric HIV infection.

The National Network of Runaway and Youth Services, supported in part by Federal funds, tries to ensure that each of its 700 affiliated youth agencies throughout the United States operates AIDS prevention/education programs. This model, if proven to be effective, should be adopted by all community programs serving runaways and homeless youths.

A considerable number of young people under age 21, while not runaways or homeless, are in need of specialized prevention services simply by virtue of being out of school and out of touch with AIDS education curricula. Many are school dropouts or are employed and living away from their families. HIV information programs for this group need to be developed and carefully targeted with a view to where these youths congregate.

4. Immigrants and Illegal Aliens

As shown in Table 1, a significant percent (12 percent) of perinatally acquired pediatric HIV cases are found among children whose mothers, or whose mothers' sexual partner, come from a country with a high prevalence of HIV infection, most commonly Haiti. Again, prevention programs will be particularly challenged to reach these individuals and families. because of language and cultural barriers, frequent mobility, and lack of participation in institutions where prevention messages are often provided. People in this group who have immigrated illegally have special reasons for fearing HIV counseling and testing, since positive results, if reported, could result in their identification and deportation.

5. Bisexual Men

Many men who have sexual relations with both men and women do not identify themselves as homosexual or bisexual, and thus may not be reached by HIV information and education programs targeting the "gay" community. However, such men—adolescents and/or adults—must be reached and educated with regard to the risk of HIV infection and transmission to their female partners and thus to their children. The education of bisexual men is also particularly important in prisons and detention centers, where homosexual activity may be practiced by otherwise heterosexual men.

6. Persons with Mental or Physical Disabilities

Other populations to date that have not been effectively reached by HIV education and prevention programs include the blind, deaf, persons with other physical or mental impairments and, in particular, adolescents in these populations. Special efforts must be made to educate youths in these populations whose behavior, coupled with living circumstances (e.g., institutionalization) may put them at risk for HIV transmission.

7. Pregnant Teenagers

Millions of adolescents become pregnant each year. Care and services should be targeted to these teens and their unborn children. HIV prevention activities should be coordinated with activities of the Secretary's Teenage Pregnancy Prevention Initiative, which already disseminates AIDS prevention information as part of its public outreach.

RECOMMENDATIONS

1. DHHS should facilitate the development, implementation, and evaluation of HIV education and prevention programs for IV drug users and their sex partners; minorities; immigrants (both legal and illegal, especially Haitians); bisexual men and their

female sex partners; and runaway/homeless and out-of-school youths.

2. DHHS should provide support to community-based efforts that incorporate multi-channel approaches, using culturally appropriate messages in the language used by, and at a literacy level appropriate to, the targeted group. Nontraditional public information techniques should be explored; in particular, non-written and even nonverbal HIV prevention messages may be appropriate. Further, credible advocates of hard-to-reach groups should be involved in formulation and delivery of prevention messages.

3. Local communities should provide HIV prevention programs, messages, and materials in locations frequented by hard-to-reach groups. Such locations will vary greatly depending on individual groups and communities, but might include bus stations, motels, shelters, convenience stores, fast-food restaurants, highway rest areas, work sites that employ transients, and the like.

4. Community and self-help groups that target specific minority groups and refugees and immigrants should incorporate HIV prevention messages and strategies into their services.

5. DHHS should either initiate a de novo training program of paid personnel or volunteers, or convert an already existing one, to provide HIV education and prevention services to populations that have not been adequately reached by governmental programs. Programs such as VISTA, which serves low-income communities, could provide a model for such a volunteer effort. Special efforts should be made to recruit volunteers or paid prevention workers from the population targeted for help. These should be seen as credible spokespersons whose messages will reflect the culture and language of the targeted population. Continuous training programs for prevention workers will also help build capacity within that community.

6. DHHS should enhance and expand its efforts to provide HIV education and prevention programs to persons with mental or physical impairments through the organizations and agencies that provide services to these populations.

ISSUE THREE:

How can we address the need for more timely counseling and testing among women of childbearing age who are at risk for HIV infection and who risk transmitting it to their children?

Factors that affect the transmission of HIV from mother to child during pregnancy or parturition are poorly defined (i.e., it is impossible to distinguish a "good" transmitter from a "poor" transmitter). Experts suspect that women in a more advanced stage of HIV disease are more likely to transmit the virus to their infants. In addition, there is evidence to suggest that pregnancy in an HIV-infected woman exacerbates the course of her HIV disease. Mindful of these facts, the Work Group supports both expanding the use of and increasing the access to HIV counseling and testing by incorporating these practices into the core of primary and prenatal health care.

In recent years, DHHS has greatly expanded its support of counseling and testing. There are now 1,100 counseling and testing sites throughout the Nation, supported by a combination of Federal, State, and local funds. Counseling and testing sites are located in many types of health care settings, including STD clinics, drug abuse treatment facilities, and TB treatment clinics. A general policy of these centers is that testing should not be done without counseling; persons who are tested are offered both pre- and post-test counseling. Counseling is provided in a one-on-one session that involves targeted prevention messages stressing avoidance of high-risk behavior.

Counseling and testing services are available to all who believe they may have been exposed to the risk of infection. Physicians and other health providers are beginning to develop consensus on when to advise testing, based on a patient's known behavioral risk factors and presenting complaints, symptoms, opportunistic diseases, or other conditions.

Clearly, women at risk of HIV infection should utilize counseling and testing services more than they do now, and physicians and other providers attending them should be more direct and forthright in advising HIV testing more frequently. If it is to be effective in preventing perinatal transmission of HIV, counseling and testing should be placed in the context of comprehensive care, including medical attention and case management.

The issue of HIV antibody testing for women of childbearing age who are at risk is a very controversial one. The controversy is complicated by the fact that the state-of-the-art of therapy is rapidly evolving, and decisions appropriate today may not be appropriate in the near future.

Arguments in support of testing for HIV seropositivity in women of childbearing age, both pregnant and nonpregnant, include the following:

- The woman may benefit from good supportive care and from more rapid diagnosis of complications of HIV infection (i.e., opportunistic infections) if her HIV status is known. In the near future, therapies may be available for pregnant women that alter the course of their HIV disease or that affect the transmission of the infection to their children, but enrollment in therapeutic trials would be limited to women who are known to be infected.
- A child may benefit if his or her mother's HIV status is known. That is, if it is known that the mother is infected, good supportive care and careful medical follow-up can be provided to the child who is at risk of infection. Again, if the child suffers from one of the complications of HIV infection, therapy can be initiated more rapidly if the child is known to be infected or at risk for infection. Some clinicians would begin prophylactic measures (e.g., antibiotics,

intravenous gamma globulin) early if the child's HIV infection was confirmed by other tests (e.g., viral culture, PCR).

- A woman who is known to be HIV-infected may be able to take measures to prevent pregnancy and/or to prevent transmission of infection to her sexual partners.

Arguments against HIV testing of women of childbearing age, whethe pregnant or not, include:

- The possibility that women will avoid medical care in general as well as prenatal care and hospital delivery if they are aware that HIV testing will take place. An analogy can be drawn with premarital HIV screening for marriage licenses, which has decreased the number of licenses applied for in at least one State.
- In view of the fact that there is no currently available, proven therapy for the treatment of HIV-infected, asymptomatic women or for HIV-infected newborns, knowledge of seropositivity seems to be an additional burden without concomitant benefit.
- A positive test result may place an individual at risk for discrimination which may include loss of job, housing, social contacts, resources for children, etc.

A related issue is deciding what advice should be given to HIV-positive women of childbearing age with respect to becoming pregnant or continuing a pregnancy. If an HIV-infected woman is diagnosed during pregnancy, she can be informed of appropriate birth control measures to prevent a second pregnancy. This is important, because many of the women in this at-risk group become pregnant again. Therefore, the delivery of a child to an HIV-infected woman may represent the most effective time for determination of her status and prevention of the birth of a second child at risk for HIV infection.

Anecdotal reports suggest that, in some centers and in some populations, advice to HIV-infected women to avoid pregnancy has had little effect. This is a serious problem that DHHS is currently trying to address. In 1987, CDC began supporting pilot projects in New York, New Jersey, and Texas to reduce the incidence of perinatal HIV infection, and seven more such projects are in the final planning stages. These projects attempt to identify seropositive women as well as seronegative women at high risk of HIV infection—for example, women who are intravenous drug abusers. Because most of these women are not in contact with any of the traditional health systems, street workers are detailed to try various intervention approaches in the hope that the women will avoid pregnancy. Results from projects such as these will be important in assessing what is effective in preventing perinatal HIV infection. Another important question to be addressed is whether strategies developed for adult women are effective for HIV-infected adolescents.

RECOMMENDATIONS

1. State and local health authorities should expand the availability and use of counseling and testing for HIV infection. Counseling and testing should be presented in a more positive context in all information and educational materials. Counseling and testing should be offered as an opportunity for individuals to protect themselves and others, particularly their unborn infants, from HIV infection. Information materials should also make clear how individuals can access counseling and testing services.

2. HIV counseling and testing must be incorporated into comprehensive care systems, and routinely offered to patients who may be at risk as part of the core of general family health care, prenatal care, family planning clinics, and STD and drug abuse treatment facilities.

3. All Federally funded STD, family planning (Title X), or other medical clinics should be required to offer HIV counseling and testing to all women, with special outreach effort to women of childbearing ages at risk for HIV infection.

4. The Department should continue to promote and accelerate research on the possible impact of HIV infection on pregnancy, and the impact of pregnancy on HIV infection. When these findings are known, they should be made available at the time of counseling and testing to HIV-positive or at-risk women of childbearing age.

5. Special training programs for HIV counseling should become part of the curriculum for Continuing Medical Education (CME) programs for primary health care providers, including internists, family practitioners, pediatricians, obstetricians and gynecologists. These programs should include: l) information about the positive aspects or benefits of counseling and testing; 2) legal and ethical issues including discrimination and confidentiality; 3) trends in and modes of HIV transmission; and 4) available experimental therapies.

6. DHHS should sponsor research in the heterosexual community on the impact of the knowledge of one's HIV antibody status on the continuation of risk behaviors, including failing to inform one's partner, engaging in unprotected sexual contact, becoming pregnant or fathering a child, using IV drugs and sharing needles, donating or attempting to donate blood or semen, and any other behaviors associated with risk of transmitting HIV to other persons.

7. The CDC must be prepared to make the results of the perinatal risk reduction projects known as soon as data are available. Target groups should include State and local health authorities and providers, as well as women at risk of HIV infection.

ISSUE FOUR:

How can we improve our understanding of risk behavior and our ability to motivate behavior change to prevent the transmission of HIV, especially in pediatric (including adolescent) populations?

Apart from the grim facts of adolescent pregnancy and STDs, little is known about adolescent sexual behavior. Similar gaps exist in our knowledge of adult sexual behavior. Knowledge about drug abuse and its role in adolescent and adult behaviors, including sexual behavior, is also lacking. In each of these areas we also lack the information and understanding to change risk-taking behaviors in adolescents and adults. All of these unknowns will have a major impact on the spread of HIV perinatally and among adolescents and pre-adolescents.

1. Behavioral Research

Answers are urgently needed to some of the following questions: 1) How and why do teens enter into sexual experiences that put them at risk of HIV as well as unintended pregnancy? 2) When do teenagers initiate contraceptive or protective measures? 3) Once begun, are contraceptive or prophylactic practices continued, and are they effective? 4) What factors are associated with prophylactic or contraceptive use following a pregnancy, birth, or STD infection among teens? We must also study the behavior of teenage males with respect to contraception, and the extent and type of homosexual encounters between males during adolescence. A final issue to explore is that of population differences among teenagers. Blacks and Hispanics are among the most important subgroups on whom more information is needed. The Work Group strongly encourages research and information gathering to clarify these issues.

Another important initiative should be a consensus conference on behavior change research and the AIDS epidemic. Such a conference should be a major source of direction for the behavioral research field, and should give due emphasis to adolescent behavior and its implications for the spread of HIV infection.

2. Prevention Evaluation Research

A number of HIV education and prevention demonstration projects are in progress. However, many of these projects are being conducted without adequate evaluation of their impact. As a result, when these projects are completed, it will be difficult, if not impossible, to measure their effects or to understand which component or components of the intervention were successful. Ideally, the methodologies of these projects should use a design in which individuals from a cohort are randomly assigned to either an experimental group that receives the intervention or a control (untreated) group. In conducting such studies, however, it is not always possible to adhere to a randomized design. Moreover, some investigators have ethical concerns about using a control group when the threat of infection is so great. In these situations, use of an alternative design would be appropriate. In any case, efforts should be made to develop valid and reliable outcome measures, particularly of self-reported behaviors.

One can wonder why many ongoing projects have been allowed to start without an evaluation component. In fact, some studies have done so to avoid the delays involved in obtaining necessary clearances. Also, the resources needed to design, implement, and analyze data from evaluation studies are not always available.

Several well-designed studies with evaluation components are being planned, (e.g., The National Health and Sexual Behavior Survey conducted jointly by CDC, NICHD, and NIMH). These projects should serve as models to others being planned.

RECOMMENDATIONS

1. DHHS should place a priority on behavioral research focused on adolescent HIV infection. Studies should encompass risk behavior; models of behavioral change interventions, including sexual and drug use behavior; and social factors and strategies to effect behavior change.

2. The Department should move forward with activities to collect, on a longitudinal basis, national baseline data that will permit a better understanding of sexual practices, attitudes, and risk behaviors of adults and adolescents of different ages and different cultural backgrounds, and make it possible to assess risks and develop intervention activities. Survey research should include proportional sampling of ethnic, racial, and cultural groups and regional variations.

3. In developing grants and contracts for behavioral and other prevention research, DHHS should require evaluation components and give them a high priority in the award criteria. The Department should also arrange for independent initiatives to evaluate major PHS prevention activities.

In particular, DHHS should mandate that:

- All agencies supporting prevention demonstration projects target funds for evaluation of these projects.
- All future prevention demonstration projects include research to measure the effectiveness of the intervention in reaching the targeted population, in being acceptable and comprehensible to the targeted population, and in reducing HIV seroprevalence rates.
- All future prevention demonstration projects be based on a clearly articulated and justified conceptual model that clearly defines the intervention approach being employed and is well documented so that, if it proves effective, it can be replicated.
- All prevention demonstration projects currently funded or being considered for funding be examined by the appropriate agency to assess the evaluation approach being considered and whether additional evaluation components are appropriate.

ISSUE FIVE:

How can we enlist the maximum contribution from the private and volunteer sectors in the prevention of pediatric HIV infection?

It is neither possible nor desirable for government alone to conduct a public information and education effort on the scale needed to prevent pediatric HIV infection. The private and volunteer sectors were in the forefront of preventive and educational efforts when the AIDS epidemic first emerged, and their expertise may be crucial to mounting prevention efforts on behalf of adolescents and children. In the interests of an entire generation imperiled by AIDS, we must continue to rely on the support of many strata of society: the media, advertisers, business and industry, national community service organizations, and private physicians and other health professionals.

The CDC's National AIDS Information and Education Program, now operative in all 50 states, is a good example of this approach. Government, in a partnership with the private and volunteer sectors, is helping local schools and community organizations to develop educational and informational materials and services. This approach, if proved effective, should be applied to the greatest possible extent to all future prevention programs for children and adolescents.

It is well known that the media (especially television and radio) can deliver powerful messages that can help shape young people's attitudes toward behavior choices. Public service announcements (PSAs) have been able to bring health-related information to nationwide audiences. Perhaps more important, broadcast media have been known to influence the social sanctioning of behavior through their portrayals. Thus, national and local media have special responsibilities in helping inform young people about AIDS and creating positive images of healthy behaviors.

Likewise, national voluntary organizations and their local affiliates have been very much involved in AIDS information and education, as have business and industry. Their efforts will also be indispensable in the task of preventing pediatric HIV infection/AIDS.

Similarly, physicians and other health professionals—especially pediatricians and obstetricians/gynecologists—are, by reason of proximity to adolescent, pediatric, and childbearing populations, strategically placed to deliver credible and timely information about HIV infection and AIDS to young people.

RECOMMENDATIONS

1. DHHS should draw upon the resources of the private and volunteer sectors, to the greatest degree possible, in the national effort to prevent pediatric (including adolescent) HIV infection and AIDS. These private and volunteer sector resources should be broadened to include the full range of pediatric HIV needs, including respite care and other health care activities, as well as prevention and education activities. Involvement of these

sectors will have a dual advantage. First, it will substantially enlarge the total prevention effort. Second, it will help make prevention programs more representative of local needs and hence more effective for the target audiences.

Top DHHS officials should seek opportunities to discuss the effect of programming content with top broadcasting executives. Advertising should be encouraged which shows or discusses the adverse consequences of risky behaviors. DHHS with the broadcasting industry should investigate opportunities for research on media-behavior linkages, both negative and positive.

2. Television stations and radio networks should provide significant prime-time scheduling targeted to youth and harder-to-reach audiences for AIDS public service announcements (PSAs). The broadcasting industry should examine the need for an ongoing process for making recommendations to individual networks and stations regarding appropriate use of PSAs, including prioritization of available PSAs by subject. Such a review and recommendation process should recognize the special importance of prevention messages for adolescents.

3. DHHS should make wider use of minority advertising specialists, seeking especially to gain the benefit of minority marketing expertise on a voluntary or cost basis. Advertising firms with special expertise in minority markets should consider creating a coalition to apply their expertise on a cost basis to issues of special interest to minorities, with AIDS (especially pediatric AIDS) as a first priority project. One possibility for such a coalition would be a minority-oriented subgroup of the Advertising Council. Whether through a formal organization or informally, DHHS should seek to tap the marketing expertise of minority advertising specialists in planning pediatric HIV information and education activities.

4. National community service organizations, especially those that sponsor youth groups or serve minorities, should be encouraged to devote significant time and resources to AIDS information efforts, counseling of youth, and other prevention-related activities. Youth groups, including youth media, should also be actively enlisted.

5. Information aimed at adolescent audiences must be available in locations where youth congregate and in the form best understood, whether video, telephone, or the written word. In addition to school-based education and youth groups, the need for information in commercial and other settings is encouraged. DHHS should seek to work with relevant trade associations, franchised businesses, and minority businesses (especially small minority business) to make use of commercial sites in the community as distribution points for AIDS information/education material.

6. Professional associations representing physicians and health workers should encourage members to be active in pediatric HIV prevention, both in their practices and on a volunteer basis. The associations should in turn be offered continuing professional education courses already available from DHHS on a range of prevention measures, including counseling and antibody testing.

ISSUE SIX:

How can information about pediatric AIDS be effectively developed and transferred into practice?

Progress in managing the spread of HIV infection will depend on how effectively we translate research findings into practice, develop new applications of existing scientific principles, and provide for timely information feedback and exchange among users.

Researchers, educators, physicians, allied health professionals, social service and other human service providers, policy makers, administrators, managers, community groups, and private citizens all have a stake in obtaining new information as it develops. Some new information may be useful to all; more typically, specific information will vary for each of the user groups—as will the information they can be expected to contribute. The nature and timeliness of the information obtained by any of these groups depend on the formal and informal networks to which they subscribe.

Typically, the more highly developed the science, the more readily information exchanges—both formal and informal—occur. For example, there have already been major national and international meetings on AIDS research, thousands of papers have appeared in the scientific and technical literature, the media have responded quickly to newsworthy findings, and those who are engaged in seminal research have been able to communicate with each other.

But in applied research and demonstration projects to improve the delivery of services related to AIDS, informational exchanges are more difficult to achieve and slower to evolve. The problems addressed in applied research and demonstration projects are more diffuse; the multiplicity of service systems and providers add complexity; solutions depend on varying client circumstances, resource availability, and access to services. Nonstandardized nomenclature confounds communication; methodological approaches are less structured and more likely to be case-specific than in basic research; data are frequently non-quantifiable; findings are more likely to be experiential; and results are often more descriptive than conclusive. Such reports do not get published in scholarly journals. Consequently, practitioners are served by fewer journals and publications. When practitioners do present AIDS-related papers at meetings, media attention is drawn to crises or failures in the delivery of services rather than successes because, in this diffuse area, successes are difficult to characterize. The recency of the HIV epidemic and an inadequate knowledge base leave few practitioners feeling expert in the field. This is especially true as it concerns children exposed to HIV infection.

In the absence of suitable means for the exchange of experimental and explanatory information, demonstration projects and community-based programs develop more slowly. One problem is duplication of efforts, especially failed efforts, due to the lack of built-in evaluation components and inadequate dissemination of results. Effective management requires continued assessment of progress and timely feedback of information to alter the intervention protocol while it is in progress. While independent evaluations may be useful, the reports are often produced after the end of the project, too late to be considered in continuing or institutionalizing the project.

Whether or not program or project evaluations are required or implemented, there is a need for an active system to inform the field of current activities and progress, of what works and what does not, of trials worthy of replication and dissemination. A system to facilitate and enhance the exchange and feedback of information among those in the field and among major funding sources would increase the effectiveness of individual applied research and demonstration projects as well as their combined effectiveness, improve follow-up activities, and help advance the field of practice. Simultaneously, there is a need for a dynamic information and referral system to serve front-line practitioners and professionals to enable them to better define problems and solutions in their day-to-day operations.

The CDC has launched several projects, and more are planned, to inform and educate the public and health care workers about pediatric AIDS. However, as more cases of infection surface, more will need to be done to improve the delivery of services and treatment beyond medical care. The National AIDS Clearinghouse is assembling a directory of service programs which will help to identify different types of programs and where they are located; however, this directory service is not designed to meet the more dynamic and analytic requirements of the field for experimental information of what is or is not working in practice, how it is made to work, or what additional information is needed to guide practitioners. CDC has given some attention to children, youth, and their families who may be vulnerable to infection, but again more attention needs to be given to how these populations can be better served. Extensive experience exists within the Department and in other parts of government. These sources should be tapped to help CDC in formulating their information programs that have a bearing on children, youth, and families.

RECOMMENDATIONS

1. One or more Program Support Center(s) should be established to work with applied researchers and community-based demonstration projects regardless of

funding source, public or private. Various major funding sources should be encouraged to participate in the support and oversight of the Center(s). The Center(s) would not assume a stewardship role but would offer supportive services, help analyze the experiences and findings across projects, help bridge the gap between research and practice, and help identify gaps in the field so that funding sources could make informed decisions regarding follow-up activities. The Center would also help to establish common terms, definitions and measures of success.

2. A pediatric AIDS network, including a dynamic information and referral system, should be established to link AIDS researchers and practitioners across geographic lines, and with providers in the private and public sectors. This network will help keep participants abreast of emerging developments in pediatric AIDS, help them to better define problems and solutions in their own communities, and provide them with an opportunity to inform and help each other.

3. An intradepartmental pediatric work group should be established (or the Secretary's Pediatric Work Group be continued) to assure continued coordination and information exchange within the Department. In particular, this group should work closely with the CDC regarding activities affecting children, youth, and families.

4. The National AIDS Clearinghouse should accelerate its plans to coordinate the efforts of existing and evolving clearinghouses, education and training centers, and others serving the field, and an efficient network with appropriate interfaces and linkages among those concerned should be established.

WORK GROUP RECOMMENDATIONS

WORK GROUP RECOMMENDATIONS FOR IMMEDIATE ACTION

1. A group of experts should be assembled to explore the possible benefits of a National Review Board whose function would be to review high priority or particularly novel therapeutic approaches, so as to hasten their clinical application to all levels of the population at risk. (Research: Issue 4)

2. A group of nationally recognized experts, including representatives from Human Development Services and child welfare agencies and organizations, should be convened to develop guidelines governing the participation of foster care children in anti-HIV investigational treatment programs. (Research: Issue 5)

3. The Centers for Disease Control (CDC) should convene a committee of expert consultants to discuss the need for expanding surveillance of HIV infection in children and adolescents and broadening the HIV classification system. This group should include representatives from State and local health departments who should help the group explore the practical implications of such an expansion. (Research: Issue 6)

4. The Secretary should encourage DHHS agencies to work collaboratively with States and community agencies to support the development of family- centered, community-based, coordinated systems of care for children with HIV infection. (Care: Issue 1)

5. Up-to-date information on HIV-related counseling and other essential HIV- related services should be distributed to all organizations and individuals who are likely to be in contact with at-risk youth—hostel directors and soup kitchen personnel as well as STD workers, staff of family planning clinics, school nurses, and others. (Care: Issue 2)

6. The Office of Human Development Services (OHDS) should encourage States and localities to explore every possible option and strategy for recruiting foster parents for HIV-infected children. (Care: Issue 3)

7. The Department should develop mechanisms to encourage enrollment of all eligible children and women with HIV infection into the Medicaid program. (Financing: Issue 1)

8. The Department should facilitate strategic planning for the care of children with HIV infection by having each operating division maximize its effort to produce data on: The number of persons eligible for Medicaid but not enrolled; the number of eligible children and adults who are infected with HIV but not symptomatic; the rate at which infection is occurring among Medicaid eligible children and adults. (Financing: Issue 1)

9. The Department should encourage all States to maximize their use of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program for providing services to eligible children with HIV infection. (Financing: Issue 2)

10. The Health Care Financing Administration and the Public Health Service should work with appropriate State officials to help design optimal care packages needed for pediatric HIV cases. (Financing: Issue 2)

11. Special education and prevention programs in settings other than schools must be developed for hard-to-reach adolescents, including minorities, drug abusers, runaways, and others. (Prevention: Issue 1)

12. All Federally funded STD, family planning (Title X), or other medical clinics should be required to offer HIV counseling and testing to all women, with special outreach efforts to women of child bearing ages at risk for HIV infection. (Prevention: Issue 3)

13. An intradepartmental pediatric work group should be established (or the Secretary's Pediatric Work Group should be continued) to assure continued coordination and information exchange within the Department. (Prevention: Issue 6)

WORK GROUP RECOMMENDATIONS REQUIRING FURTHER STUDY

1. The Department should support substantial increases in funding for all aspects of pediatric and maternal HIV disease research. This funding should be discernible as a separate item in departmental budgets. (Research: Issue 1)

2. The Department should foster the development and funding of small, short- term grants or contracts for feasibility projects which would allow the academic and small business research communities to design and test innovative ideas. This would be a cost-effective way to evaluate ideas and therapeutic interventions in a timely fashion and maximize the productivity of these groups, which have a contribution to make to the anti-AIDS effort. (Research: Issue 1)

3. The Department should develop legislation that would allow programs to recruit, train, and retain both junior and senior level clinicians, investigators, and health care specialists who would focus their efforts on the care and treatment of pediatric HIV patients. (Research: Issue 2)

4. The number of sites of the NIH-supported AIDS Clinical Trials Group (ACTG) should be increased so as to facilitate the evaluation of promising new agents for the treatment of HIV-infected children. The location of these investigational treatment programs should be in areas of the country where children with AIDS are most heavily concentrated. (Research: Issue 3)

5. The Food and Drug Administration should consider revising its guidelines to permit early testing of promising agents in infants, children, and adolescents, simultaneously with their Phase I testing in adults. The FDA should issue treatment IND (Investigational New Drug) applications for research on promising new agents in children in tandem with applications for similar research in adults. (Research: Issue 4)

6. The Federal agencies should consider targeting special efforts to address risk reduction and care for developmentally delayed and other persons with mental or physical disabilities and should encourage support of efforts to study the developmental and neurological impairments resulting from HIV infection in children. (Care: Issue 1)

7. The Department should consider the development of an initiative that would encourage programs that serve undocumented and illegal aliens to emphasize services to parents and children at risk of HIV infection. (Financing: Issue 1)

8. DHHS should support a comprehensive study on the cost, financing, and quality of health care services for HIV-related conditions. Information should be developed on total national cost of the disease, variation in resource utilization by different risk groups or geographic areas, distribution of the financial burdens across payers, and the future public and private resources that will be needed as the epidemic changes.(Financing: Issue 2)

9. The Department should convene representatives from State Medicaid programs, from the Health Care Financing Administration, and from the Federal Maternal and Child Health program to plan a coordinated strategy for ensuring that publicly financed or subsidized health care services, as well as drug abuse treatment, are available to people who lack family or personal resources. (Financing: Issue 3)

10. The Department should encourage the expansion of the HIV care model to include benefits specialists and/or financial advisors who can assist families in meeting their cash and subsistence needs as well as their medical needs. This approach may be piloted and disseminated through programs such as Pediatric AIDS Health Care Demonstration projects (under Public Law 100-102). (Financing: Issue 4)

11. AIDS education should be part of a comprehensive health and safety education (CHASE) program. (Prevention: Issue 1)

12. DHHS should either initiate a de novo training program of paid personnel or volunteers, or convert an already existing one, to provide HIV education and prevention services to populations that have not been adequately reached by governmental programs. (Prevention: Issue 2)

13. DHHS should enhance and expand its efforts to provide HIV education and prevention programs to persons with mental or physical impairments through the organizations and agencies that provide services to these populations. (Prevention: Issue 2)

14. DHHS should place a priority on behavioral research focused on adolescent HIV infection. Studies should encompass risk behavior; models of behavioral change interventions, including sexual and drug use behavior; and social factors and strate-

gies to effect behavior change. (Prevention: Issue 4)

15. All agencies supporting prevention demonstration projects should target funds for evaluation of these projects. (Prevention: Issue 4)

16. DHHS should draw upon the resources of the private and volunteer sectors, to the greatest degree possible, in the national effort to prevent pediatric, including adolescent, HIV infection and AIDS. Top DHHS officials should seek opportunities to discuss the effect of programming content with top broadcasting executives. (Prevention: Issue 5)

WORK GROUP RECOMMENDATIONS FOR STATES

1. States should consider re-evaluating their current policies and procedures to ensure that HIV-infected children who are wards of the State can participate in appropriate clinical trials and treatment, with all the protection accorded to any child. (Research: Issue 5)

2. State agencies should have access to a substantive data base regarding the unique characteristics of HIV infection, which they could use in making informed decisions on behalf of the children in their care. (Research: Issue 5)

3. States should encourage the dissemination of materials through pertinent national or state clearinghouses, newsletters, and project meetings, together with the provision of names and telephone numbers of key persons in Federal and/or local agencies who can provide information. (Care: Issue 1)

4. States should confront the possibility that congregate care may be needed at some time for some HIV-infected children. In preparation for this contingency, State and local welfare officials should be encouraged to join with corresponding health authorities to explore promising models for congregate care of HIV-infected children. These congregate care facilities should be used only as intermediate stops on the way to family placement. Federal officials are urged to endorse this view through program letters, grant reviews, and child welfare forums. (Care: Issue 4)

5. States and localities should consider recognizing relatives as an appropriate source of foster care, subject to the same review and afforded the same benefits as other foster parents. (Care: Issue 5)

6. State child welfare agencies should consider ways to facilitate and accelerate the certification and licensing of potential foster parents for HIV-infected children, particularly when these individuals are relatives. Expedited action, however, should not compromise the integrity of the foster home study and review process. (Care: Issue 5)

7. States should fully and affirmatively consider informing relatives willing to foster children with HIV infection of any financial, medical, or other support services available to them in this capacity. (Care: Issue 5)

8. States should be reminded that Federal fiscal participation in foster care maintenance payments under title IV-E is provided to relatives as well as non-relatives. (Care: Issue 5)

9. States should consider including "medically needy" provisions under their Medicaid programs. (Financing: Issue 1)

10. States should consider the development and utilization of Home and Community-Based Waivers. These should give special consideration to the array of services and benefits that are needed for children with HIV infection and disease. (Financing: Issue 2)

11. All States should consider developing optional case management services in cooperation with the State's Maternal and Child Health program, and ensure that these services are tailored to meet the special needs of eligible children with HIV infection and disease. (Financing: Issue 2)

12. All States should consider the inclusion of HIV testing, which has recently become a covered service under Early and Periodic Screening, Diagnosis and Treatment (EPSDT), in their screening programs. (Financing: Issue 2)

13. State social services and welfare agencies should examine the special needs of medically impaired families and individuals, and develop improved outreach programs. (Financing: Issue 4)

14. States should take advantage of allowable State plan options to facilitate the process whereby medically impaired families apply for financial and social services so that this process does not become an extra burden in itself. (Financing: Issue 4)

15. Every local school board (including boards responsible for public, parochial, and private schools) should address the need for HIV education and determine, with input from parents, teachers, students themselves, community leaders, and other legitimately concerned parties, the content and timing of such HIV education in local schools. (Prevention: Issue 1)

16. State governments should consider requiring HIV education as a condition for state funding at the local school level. Education continues to be essential to alert youths about the risks of drug abuse and sexual behaviors that may expose them to HIV infection. (Prevention: Issue 1)

17. Local communities should provide HIV prevention programs, messages, and materials in locations frequented by hard-to-reach groups. Such locations will vary greatly depending on individual groups and communities, but might include bus stations, motels, shelters, convenience stores, fast-food restaurants, highway rest areas, work sites that employ transients, and the like. (Prevention: Issue 2)

18. State and local health authorities should expand the availability and use of counseling and testing for HIV infection. Counseling and testing should be presented in a more positive context in all information and education materials. (Prevention: Issue 3)

CHARTS AND TABLES

CHART 1:

Five Leading Causes of Death vs. AIDS in Persons Fifteen to Twenty-Four Years of Age: 1980-1987

■ Accidents

● Homicide

□ Suicide

○ Malignant Neoplasms

▲ Diseases of the Heart

✖ AIDS

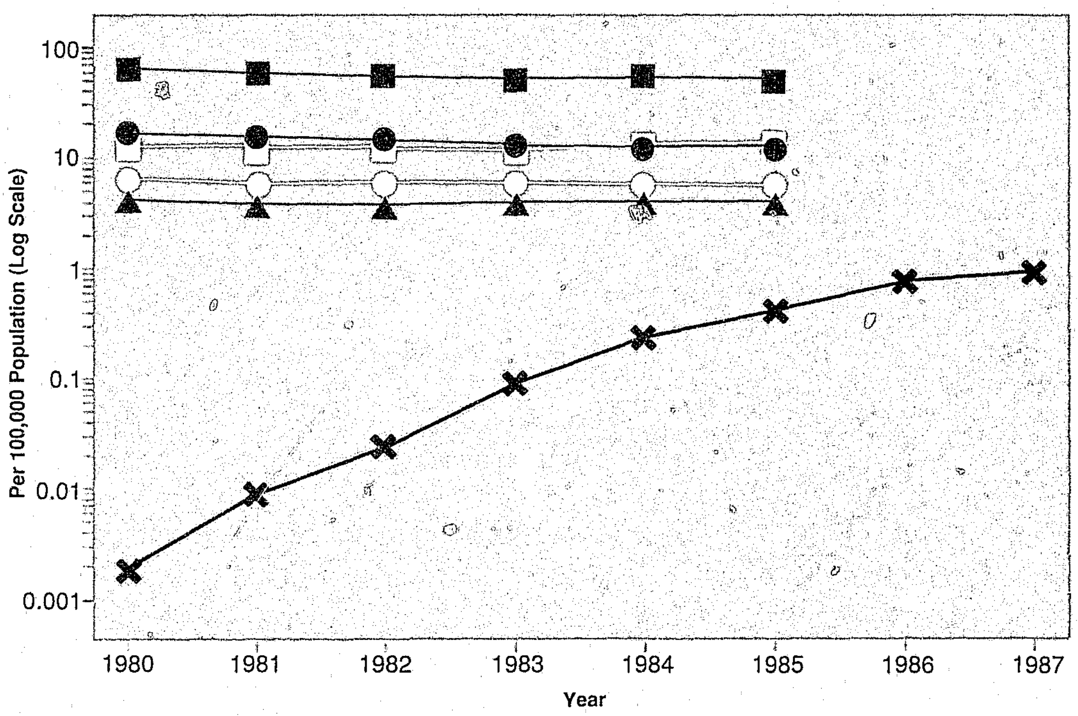


CHART 2:

Sixth Through Tenth Leading Causes of Death vs. AIDS in Persons Fifteen to Twenty-Four Years of Age: 1980-1987

■ Congenital Anomalies

● Pneumonia and Influenza

□ Cerebrovascular Disease

○ COPD and Allied Conditions

▲ Anemias

✖ AIDS

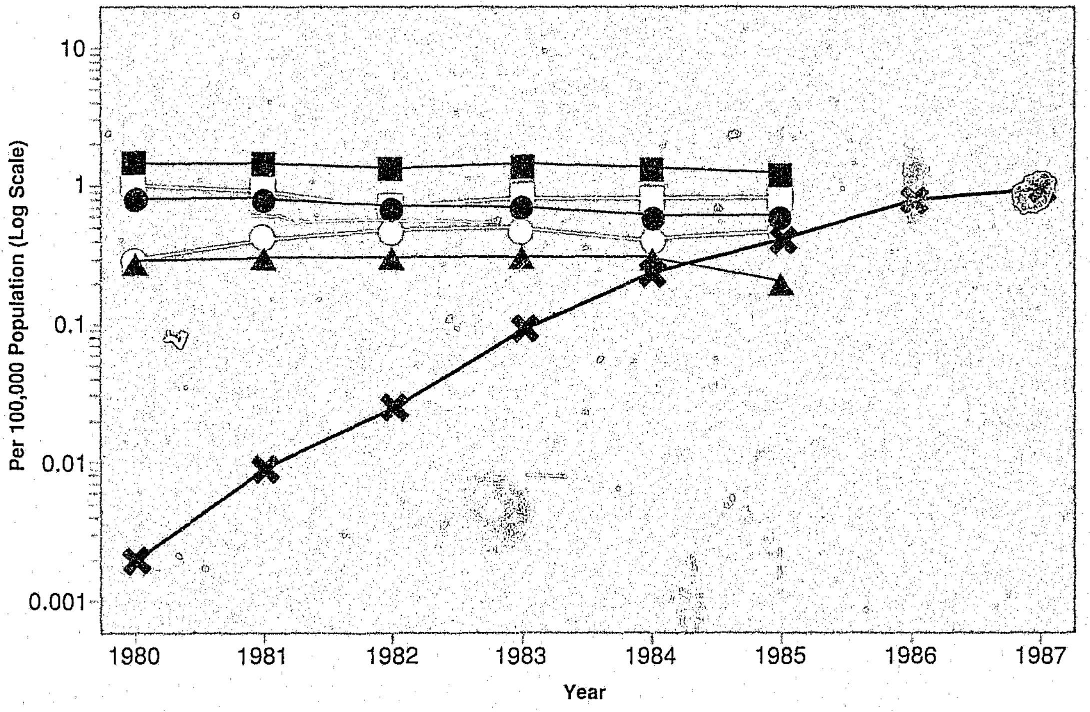


CHART 3:

Five Leading Causes of Death vs. AIDS in Children Five to Fourteen Years of Age: 1980-1987

- ■ Accidents
- ● Congenital Anomalies
- □ Malignant Neoplasms
- ○ Homicide
- ▲ Diseases of the Heart
- ✖ AIDS

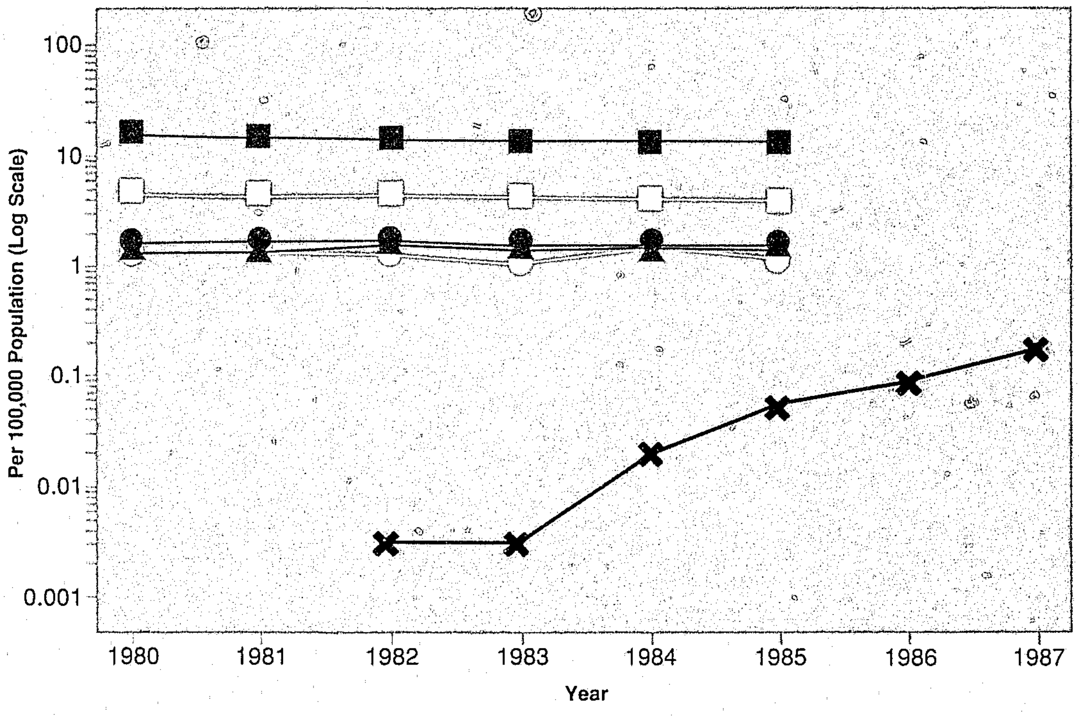


CHART 4:

Sixth Through Tenth Leading Causes of Death vs. AIDS in Children Five to Fourteen Years of Age: 1980-1987

- ■ Suicide
- ● COPD and Allied Conditions
- □ Pneumonia and Influenza
- ○ Benign Neoplasms
- ▲ Cerebrovascular Diseases
- ✖ AIDS

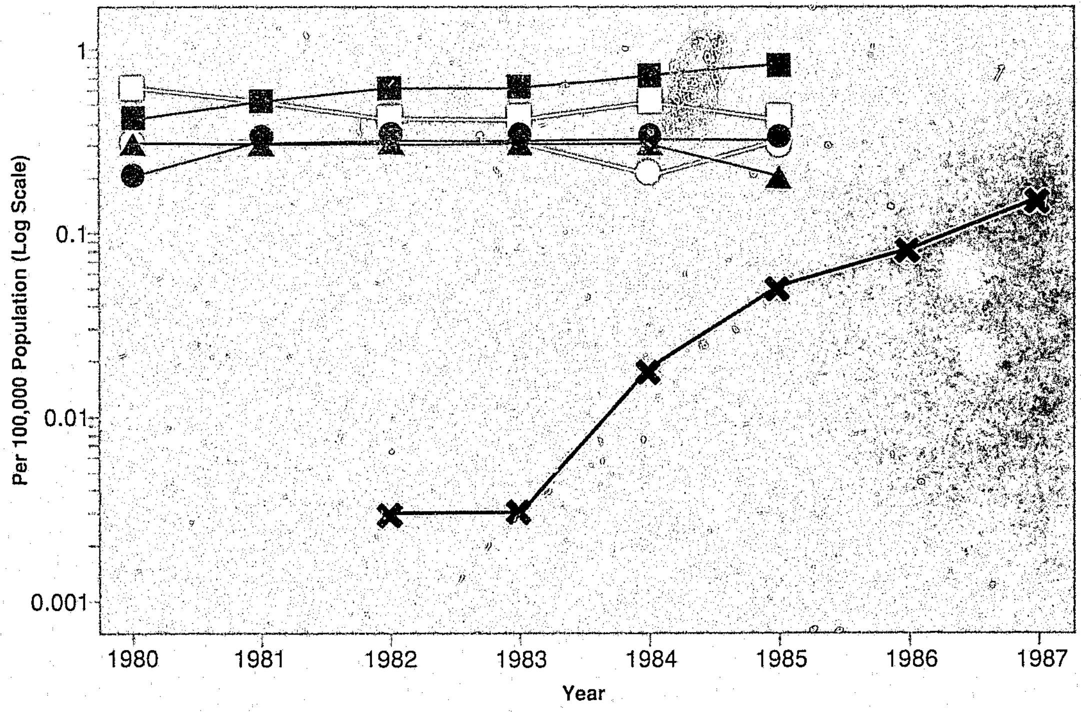


CHART 5:

Five Leading Causes of Death vs. AIDS in Children One to Four Years of Age: 1980-1987

- ■ Accidents
- ● Malignant Neoplasms
- □ Congenital Anomalies
- ○ Diseases of the Heart
- ▲ Homicide
- ✖ AIDS

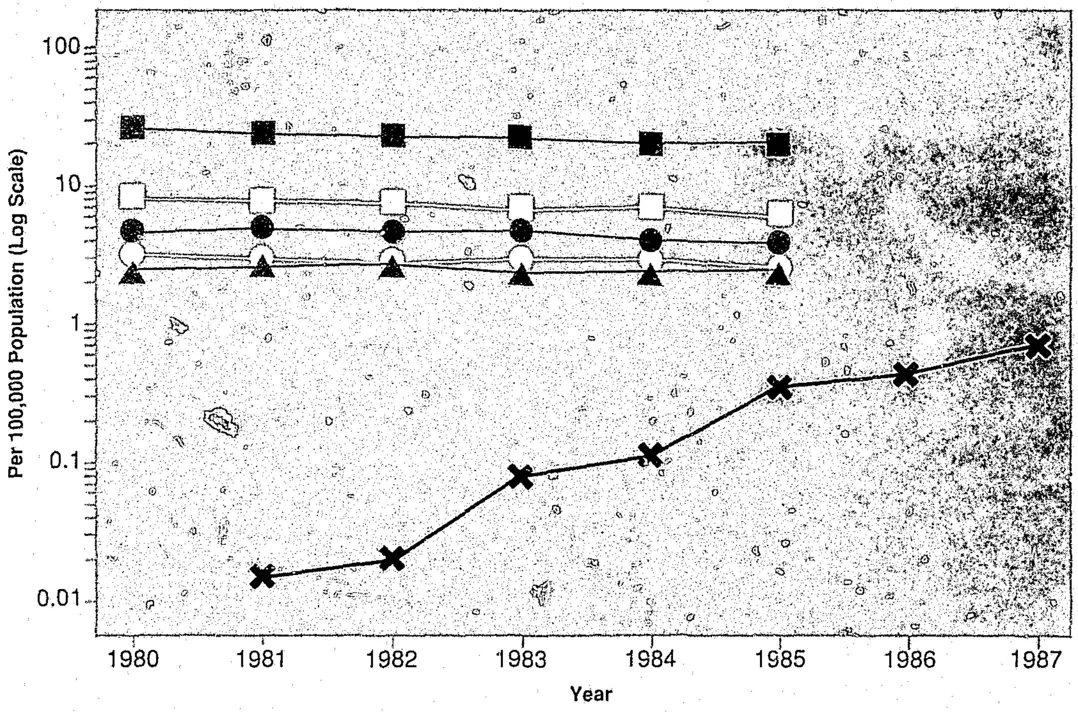


CHART 6:

Sixth Through Tenth Leading Causes of Death vs. AIDS in Children One to Four Years of Age: 1980-1987

- ■ Pneumonia and Influenza
- ● Perinatal Period Complications
- □ Meningitis
- ○ Septicemia
- ▲ Meningococcal Infection
- ✖ AIDS

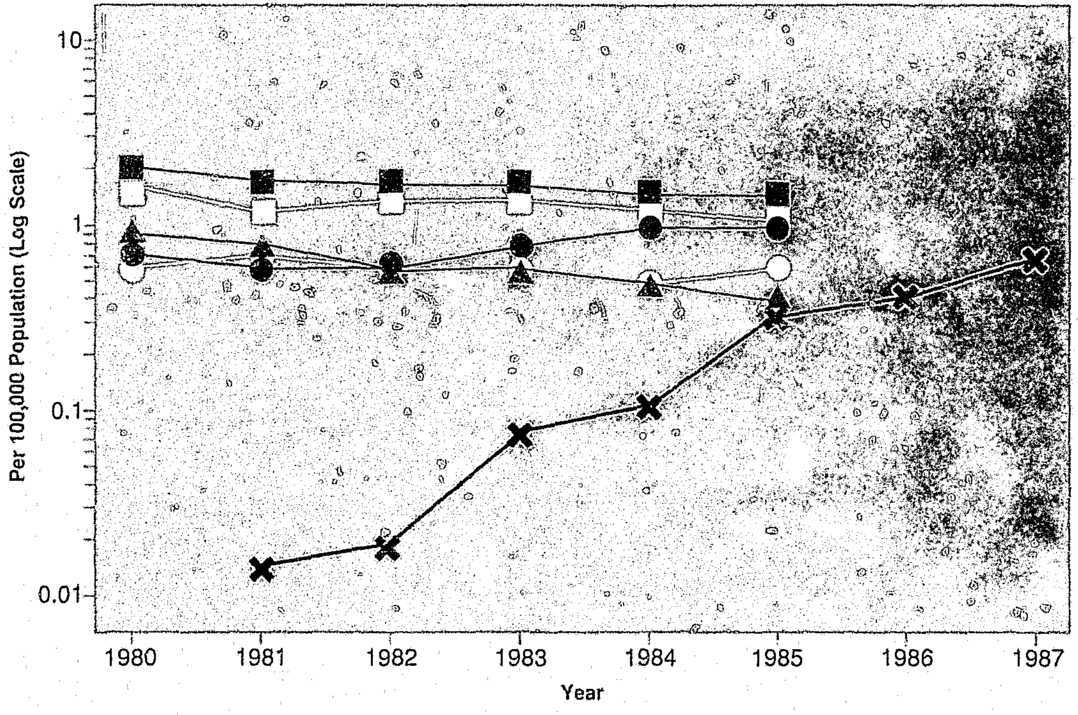
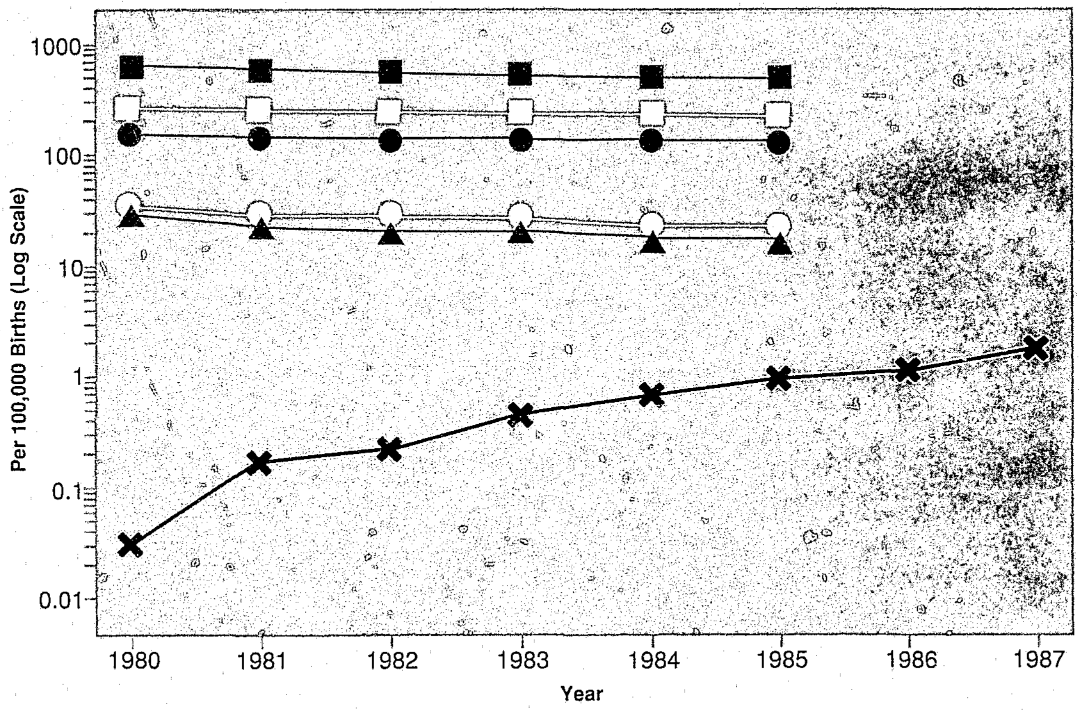


CHART 7:

Five Leading Causes of Death vs. AIDS in Children Less Than One Year of Age: 1980-1987



■ Perinatal Period Complications

● SIDS

□ Congenital Anomalies

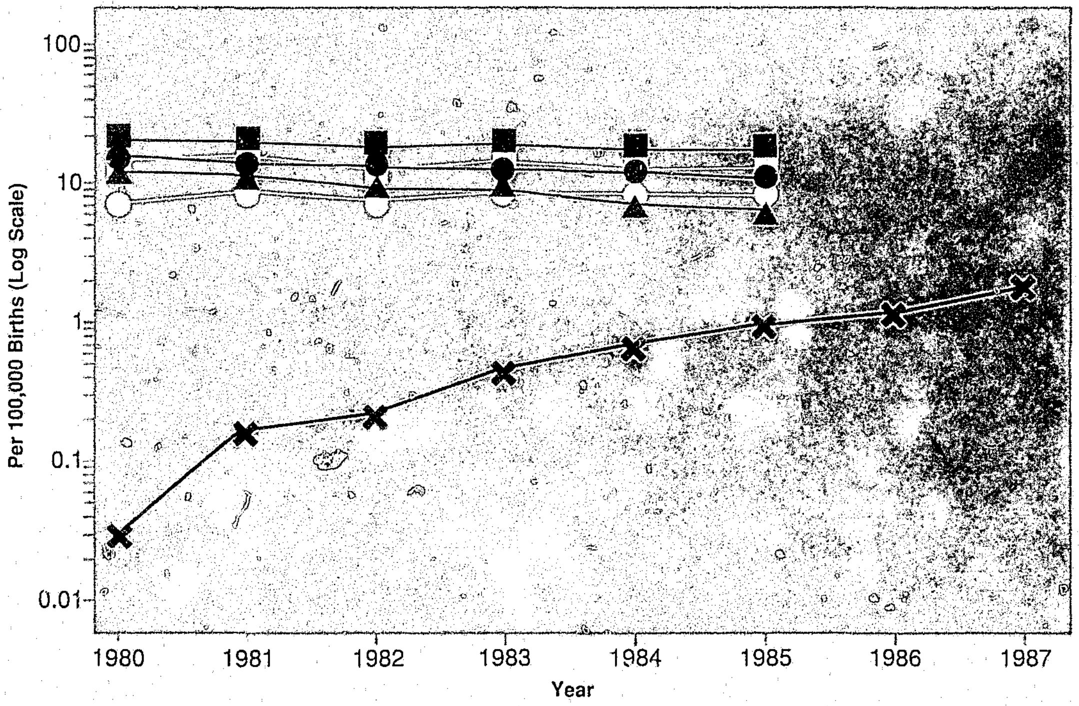
○ Accidents

▲ Pneumonia and Influenza

✕ AIDS

CHART 8:

Sixth Through Tenth Leading Causes of Death vs. AIDS in Children Less Than One Year of Age: 1980-1987



■ Respiratory Disease

● Diseases of the Digestive System

□ Diseases of the Nervous System

○ Septicemia

▲ Meningitis

✕ AIDS

CHART 9:

Five Leading Causes of Death vs. AIDS Deaths, by Race in Persons Fifteen to Twenty-Four Years of Age: 1985

☐ White

▨ Black

▨ All Others

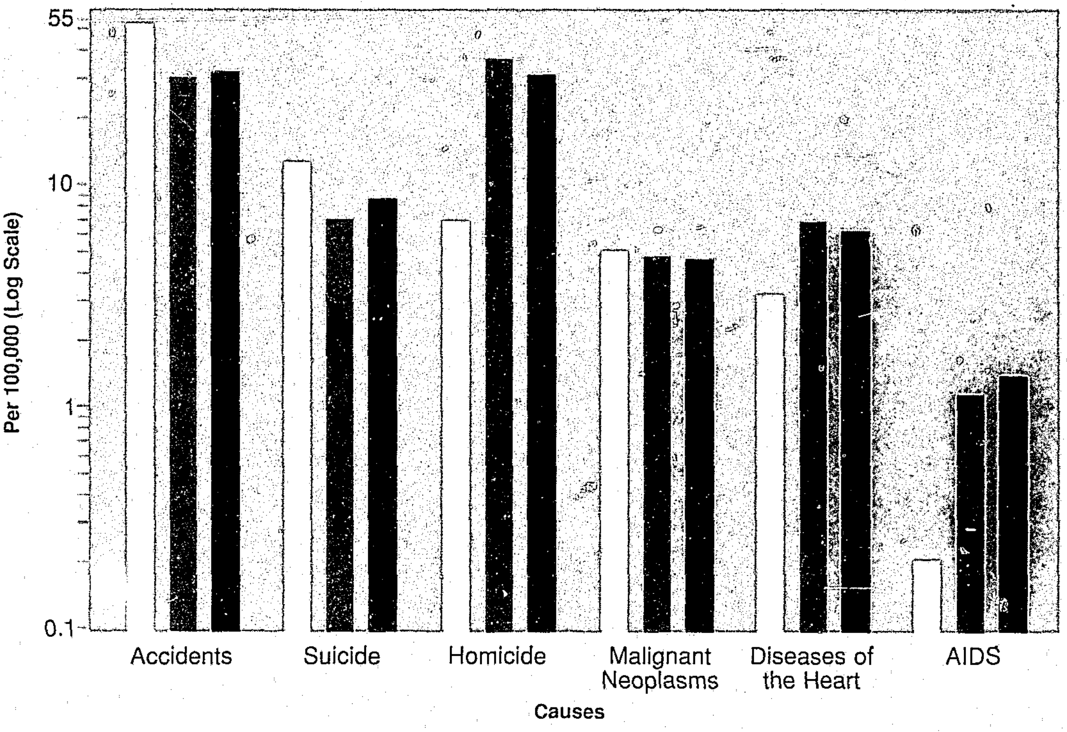


CHART 10:

Five Leading Causes of Death vs. AIDS Deaths, by Race in Children Five to Fourteen Years of Age: 1985

☐ White

▨ Black

▨ All Others

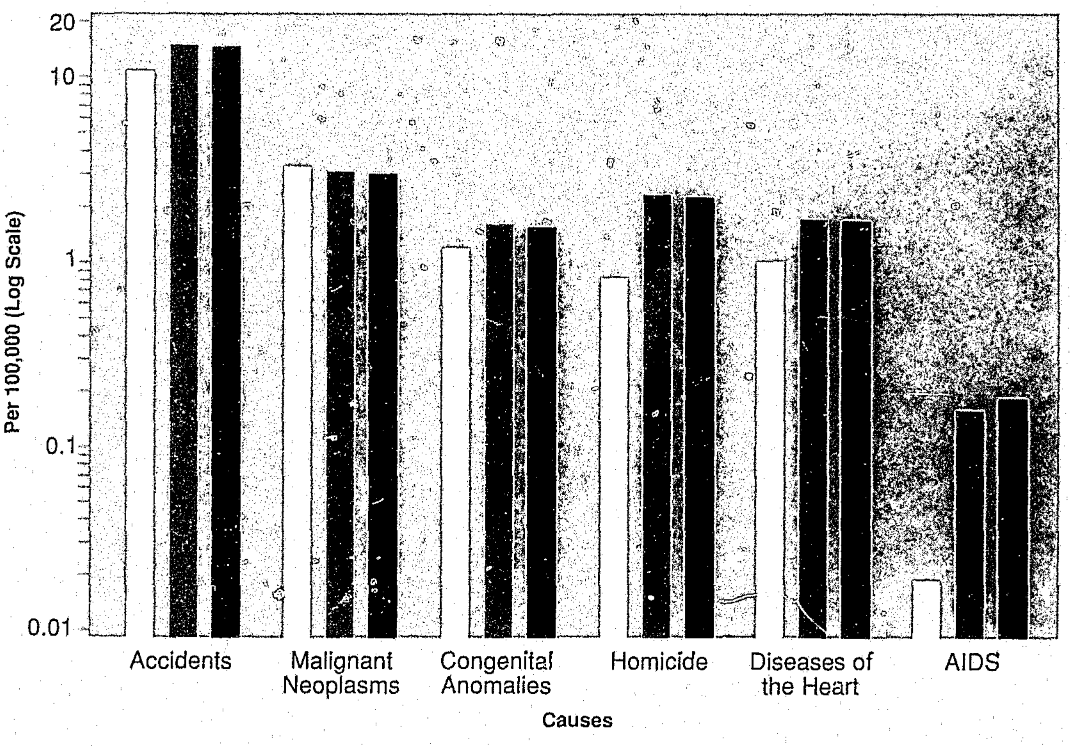


CHART 11:

Five Leading Causes of Death vs. AIDS Deaths, by Race in Children One to Four Years of Age: 1985

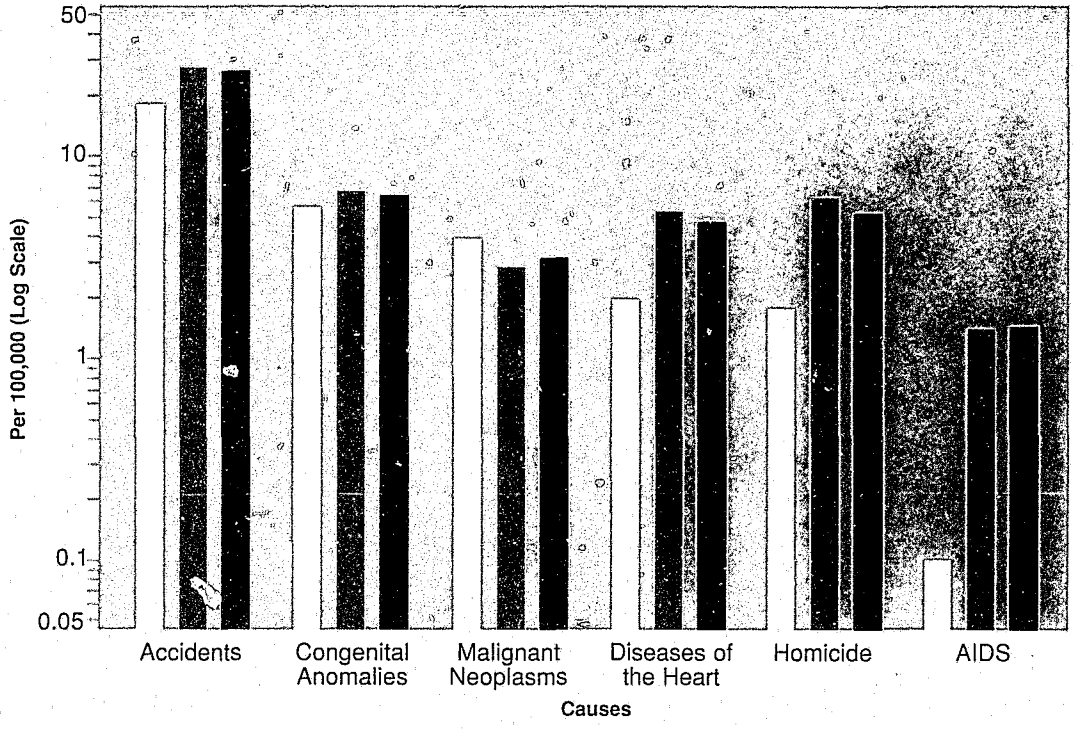


CHART 12:

Five Leading Causes of Death vs. AIDS Deaths, by Race in Children Less Than One Year of Age: 1985

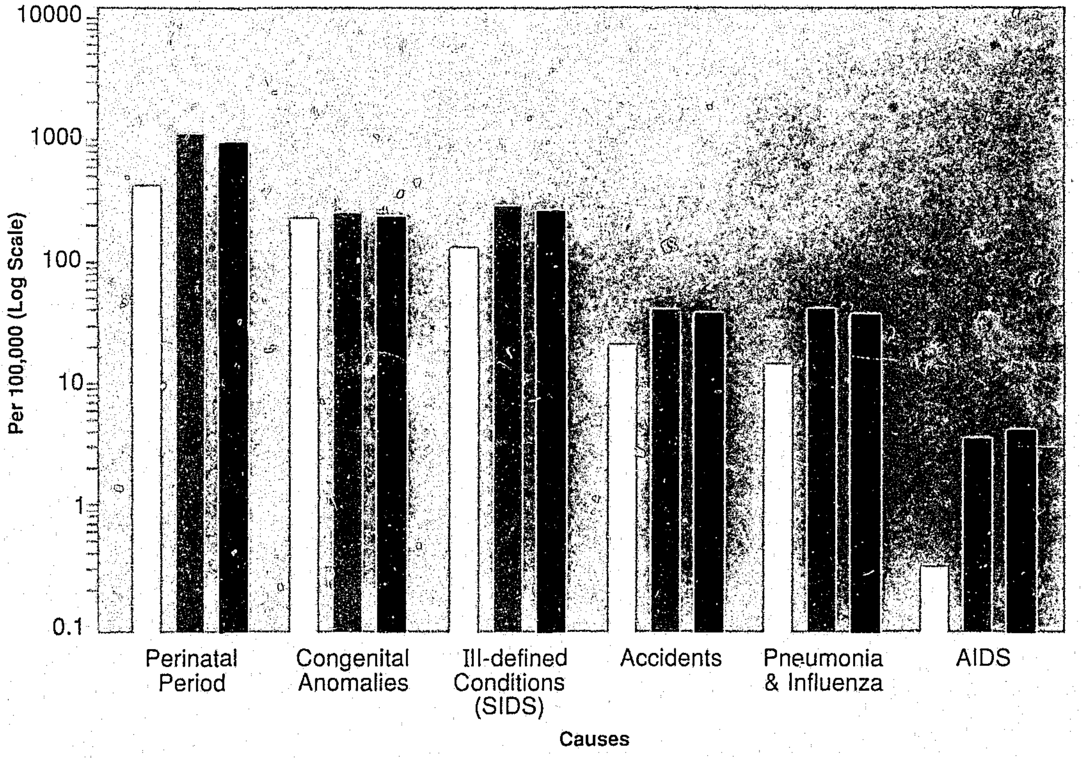


CHART 13:

Reported Adolescent/ Young Adult AIDS, Cases by Age at Diagnosis: 1981-1988

Source: Centers for Disease Control

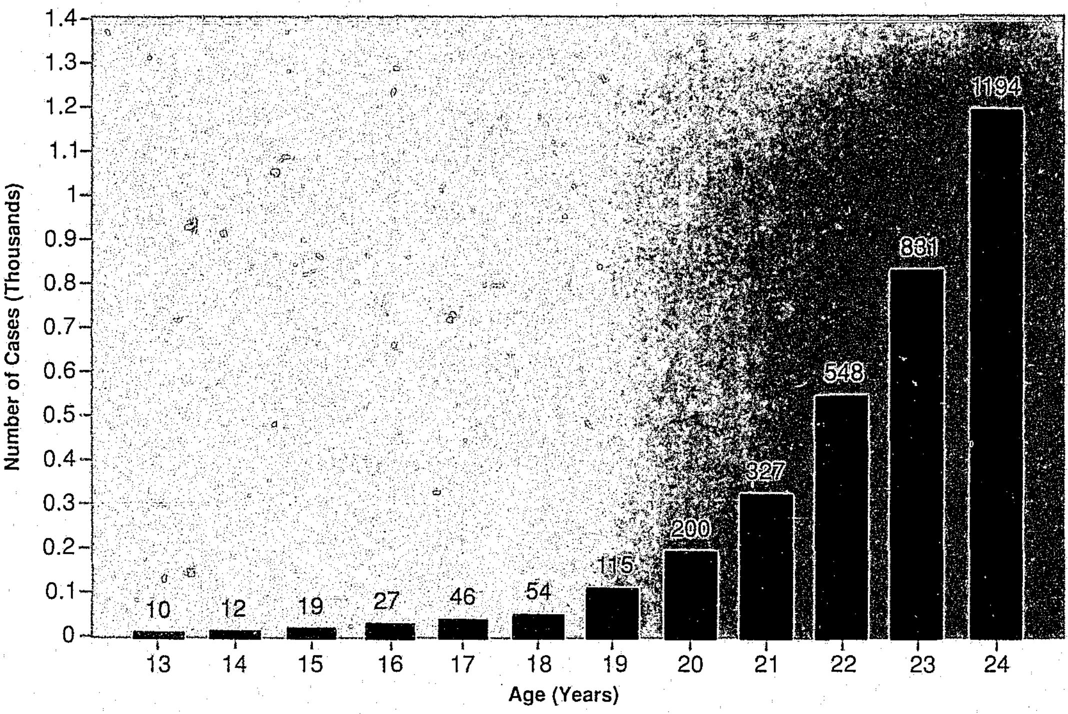


CHART 14:

Reported Adolescent/Young Adult AIDS, Cases by Year of Diagnosis: 1981-1987

Source: Centers for Disease Control

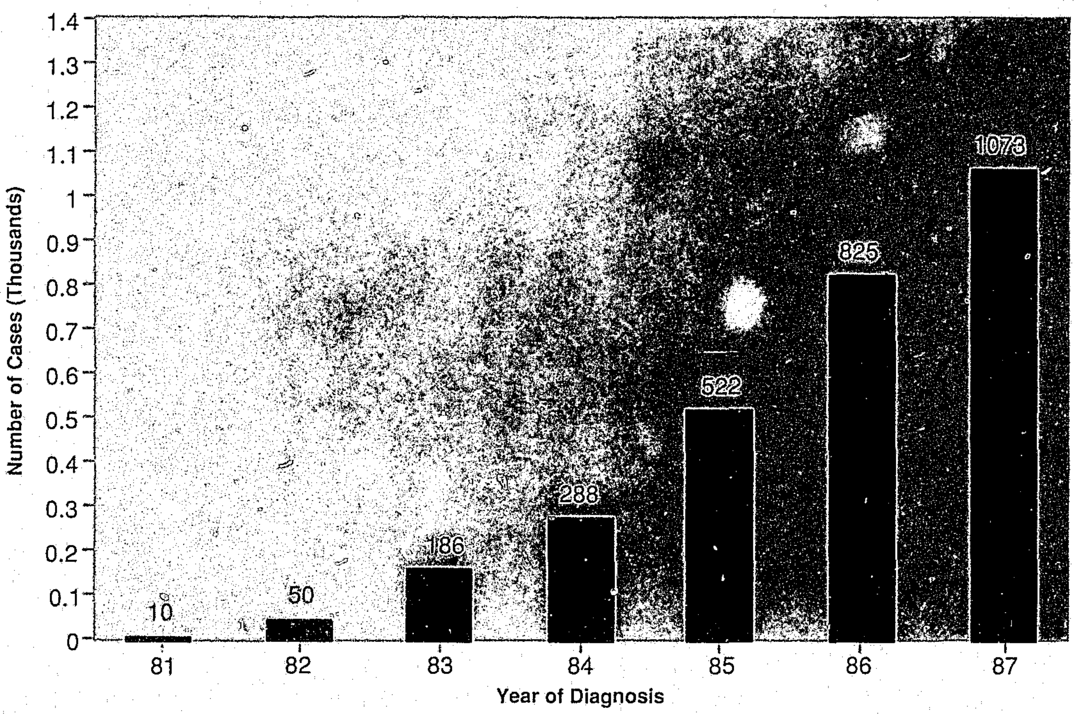


CHART 15:

Reported Adolescent and Young Adult AIDS Cases by Sex and Transmission Category: 1981-1988

- ▨ Homosexual/Bisexual
- ☐ IV Drug Abusers
- ■ Homosexual IVDA
- ▩ Hemophilia
- ■ Heterosexual Contact
- ▩ Transfusion
- ▨ Undetermined

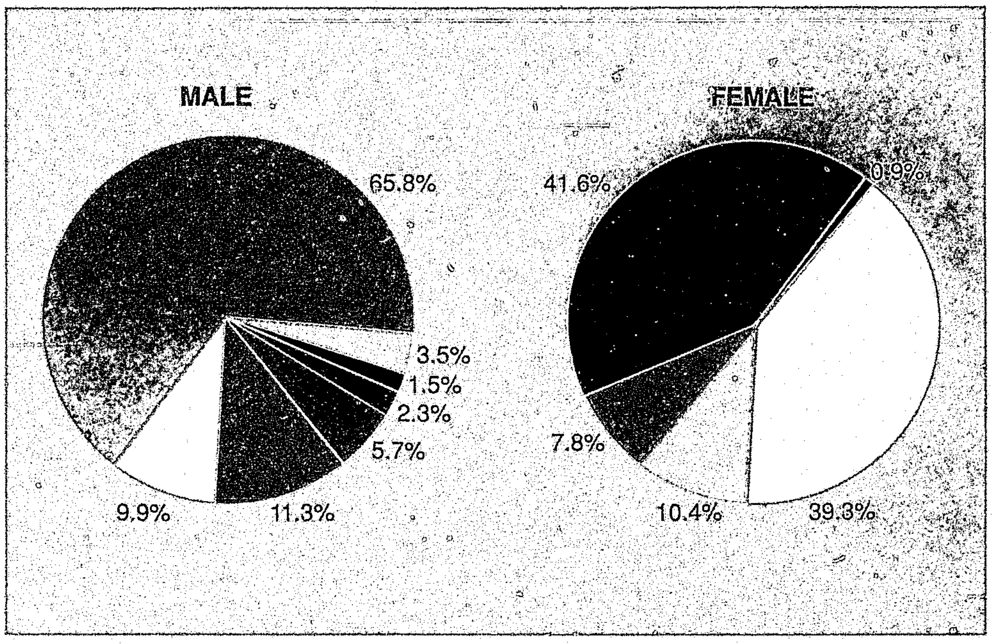
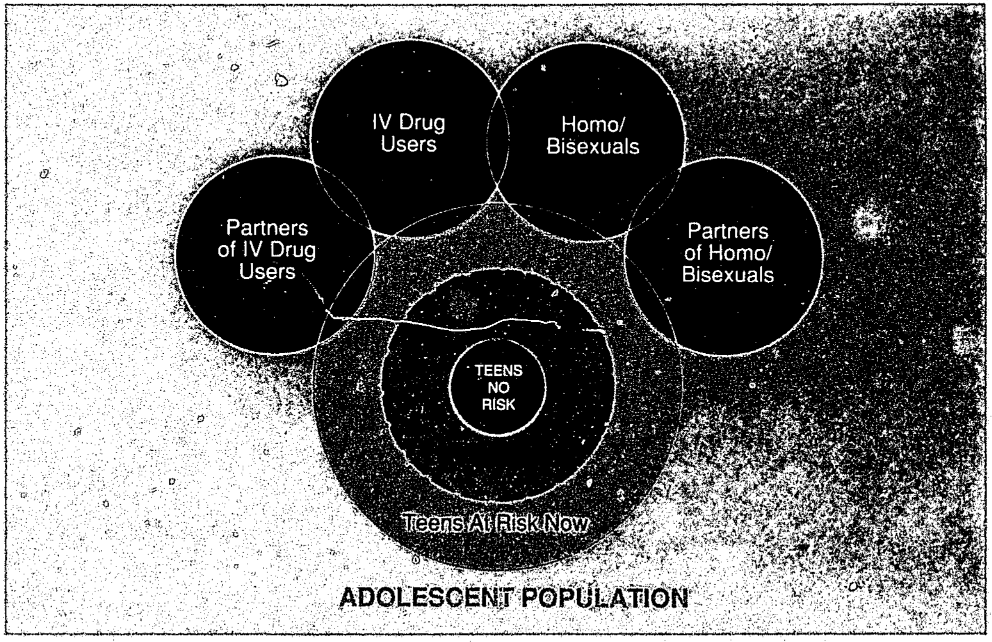


CHART 16:

Conceptual Framework

We must create meaningful categories of risk within the teenage population in order to target specific recommendations for specific groups. The teenage population does not have a wall around it nor is the infected adult population quarantined.

This figure provides a conceptual framework in which we might view adolescents.



Source: Karen Hein, M.D.

CHART 17:

Employment and Population (Percent Change 1976-1986)

▨ Employment Change

▨ Population

Source: Bureau of the Census (population statistics) and Bureau of Labor Statistics (employment statistics)

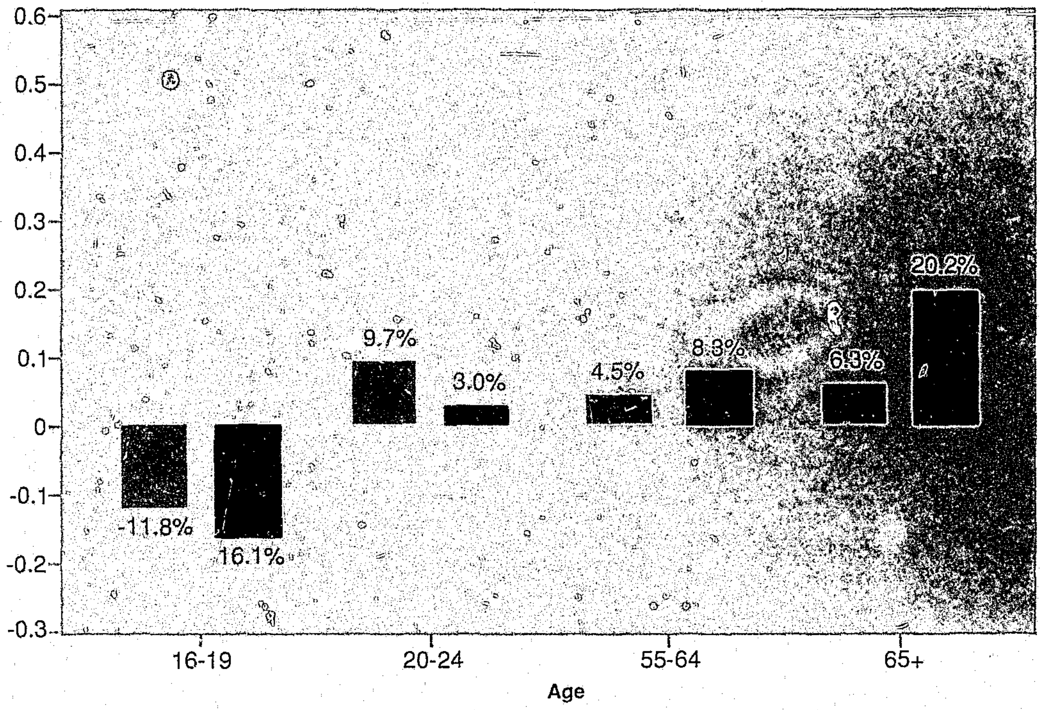


CHART 18:

Ratio of Working Age to Elderly Population: 1980-2060 (Ratio of 18 to 64 years to 65+ Years)

☐ Highest Working-Age to Elderly

▨ Middle Working-Age to Elderly

▨ Lowest Working-Age to Elderly

Source: U.S. Bureau of the Census

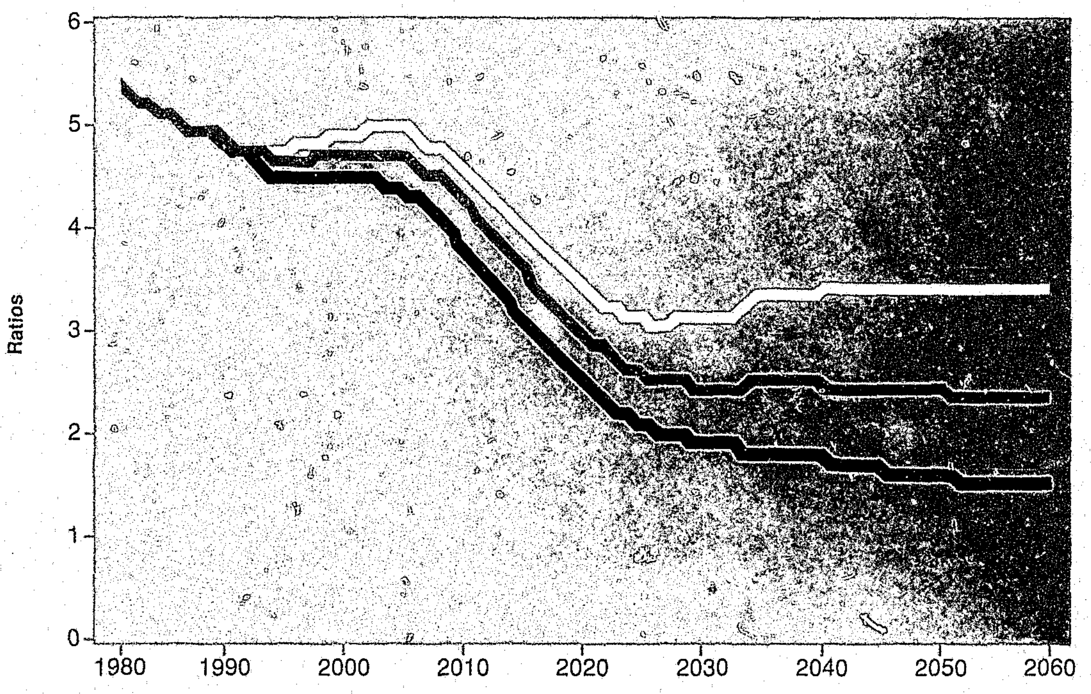


TABLE 1:

Transmission Categories for Children with AIDS Under Age 13 Reported to the Centers for Disease Control (Cumulative, 1981 to July 1, 1988)

Source: Centers for Disease Control

Category	No. Cases	Percent
Children with hemophilia	60	5.7
Transfusion-acquired	136	13.0
Undetermined	39	3.7
Perinatally acquired*:	**814**	**77.6**
■ Mother an IV drug abuser (IVDA)	(444)	(54.5)
■ Mother's sex partner an IVDA	(152)	(18.7)
■ Mother from a country with high prevalence of HIV infection**	(93)	(11.4)
■ Mother HIV^{+}, but specific risk factor unknown	(48)	(5.9)
■ Mother's sex partner HIV^{+}, but specific risk factor unknown	(27)	(3.3)
■ Mother's sex partner a bisexual male	(21)	(2.6)
■ Mother HIV^{+}, transfusion-acquired	(20)	(2.5)
■ Mother's sex partner a hemophiliac	(6)	(.7)
■ Mother's sex partner from country with high prevalence of HIV infection**	(3)	(.4)
Total cases	**1,049**	**100.0**

*Mother's seropositivity not documented in all cases, but assumed to be 100 percent

**Most commonly, Haiti.

TABLE 2:

General Clinical Research Centers (GCRC) AIDS Research

FY	Subprojects	Support
87*	79	$3,216,921

Number of Adult Subprojects - 74	$2,895,288
Normalized costs for one adult inpatient day	$ 750
Normalized costs for one adult outpatient visit	$ 251
Number of Pediatric Subprojects - 5	$ 321,633
Normalized costs of one pediatric inpatient day	$ 1,579
Normalized costs of one pediatric outpatient visit	$ 526

*Covers overlapping fiscal year; FY 86 and only a portion of FY 87

During the funding period covered for this report, AIDS-related research for adult patients required an average of 4.6 research outpatient visits to 1.0 inpatient research day. For pediatric patients that relationship was approximately 1 outpatient visit to 1 inpatient day. For both pediatric and adult patients, the cost of inpatient research is greater.

Updated information is currently being compiled, based on GCRC FY 87 annual report information which reflects FY 87 and part of FY 88 data. Initial analysis revealed more inpatient research patient days for adult AIDS-related research. A much greater number of pediatric AIDS-related research days were supported at Centers and a greater number of Centers are hosting AIDS-related pediatric research. Pediatric AIDS-related research areas include vertical transmission of the human immunodeficiency virus (HIV), natural history of the disease in children, horizontal HIV transmission, refining diagnostic criteria for infants between 0 and 15 months after birth, host and environmental factors affecting the course of infection, therapeutic intervention with azidothymidine (AZT) and hyperimmune gamma globulin, as well as neurologic and developmental abnormalities.

TABLE 3:

Pediatric AIDS and HIV Related Activities, Department of Health and Human Services

Agency	Project Title	Category	Functional Category	Funding 87 ($000s)	Funding 88 ($000s)
ADAMHA	NIDA AIDS Center Grant/Part Adolescents Education	Prevention	Persons at Risk	185	185
CDC	Prevent Perinatal Transmission/NJ	Prevention	Prevention	0	1
CDC	School Health Education	Prevention	Education	12,000	25,000
HRSA	Implement Surgeon General's Report	Prevention	Education	9	
HRSA	AIDS Regional Education and Training	Prevention	Education/Training		556
HRSA	Sprans-Model to Prevent HIV	Prevention	Prevention	225	
HRSA	AIDS Regional Education and Training	Prevention	Education/Training		594
HRSA	AIDS Regional Education and Training	Prevention	Education/Training	1,200	
HRSA	AIDS Regional Education and Training	Prevention	Education/Training		455
NIAID	Information and Education	Prevention	Education	0	239
NICHD	Develop Improved Spermicidal Formulation with Virucidal Activity	Prevention	Prevention	0	900
NICHD	Condoms/Prevent Heterosexual Transmission/Zaire	Prevention	Prevention	0	800
NICHD	AIDS Education for Children/Parents	Prevention	Education	27	200
NICHD	Societal/Behavioral Aspects/Health/Fertility-Related Behavior	Prevention	Behavioral	0	492
NICHD	Contraceptive Behavior of Teen Women/Partners	Prevention	Education	290	250
OMH/OASH	Technical Assistance for Minority Organizations	Prevention	Education	0	150
OMH/OASH	AIDS Ed/Prevention Minority Adults/Adolescents	Prevention	Education	80	0
Total Prevention/Education				**14,016**	**29,822**
NCI	Division of Cancer Etiology	Research		1,549	1,647
NICHD	NAS Committee/AIDS Research: Social/Behavioral Sciences	Research	Behavioral	50	50
NICHD	Behavioral Aspects of AIDS Prevention Child/Adolescents	Research	Behavioral	0	750
NICHD	Relation Between STD/AIDS/Fertility-Related Behavior	Research	Behavioral	38	700
NICHD	Determinants of Contraceptive Use in Adolescent Males	Research	Contraception	31	54
NICHD	Domestic Barrier Contraception Prevention Trial	Research	Contraception	454	1,000
NICHD	Impact of HIV Infect in Pregnancy	Research	Co-Factors	0	923
ADAMHA	AIDS Risk/Pregnant IV Drug Users/Children	Research	Co-Factors	52	56

Agency	Project Title	Category	Functional Category	Funding 87 ($000s)	Funding 88 ($000s)
NICHD	Support/Developmental Outcome in HIV Infected Children/Infants	Research	Developmental	150	1,205
NICHD	Support for Epid Studies of HIV/Related Viruses	Research	Epidemiology	697	0
ADAMHA	AIDS Associated Retrovirus Infection in Children	Research	Epidemiology	114	123
ADAMHA	AIDS Risk/Pregnant IV Drug Users/Children	Research	Epidemiology	79	84
NICHD	Nat'l Longitudinal Survey of Youth	Research	Epidemiology	0	75
CDC	Epi/Household Contact/Heterosexual Contact	Research	Epidemiology	727	900
CDC	Epi/HIV Infection in Adolescents	Research	Epidemiology	0	539
NICHD	1987 National Survey of Family Growth	Research	Epidemiology	193	50
NICHD	Perinat/Pediatric AIDS/HIV Disease/African Women/Children	Research	Epidemiology	279	290
NICHD	Risk HIV Infection in Various Methods of Contraception	Research	Epidemiology	0	500
NICHD	AIDS/Breast Feeding in Africa	Research	Epidemiology	0	200
NICHD	Bay Area Aids Center	Research	Epidemiology	0	1,383
CDC	Transfused Blood Study	Research	Epidemiology	551	400
HRSA	Sprans-Effects of HIV on Development of Hemophilic Children	Research	Epidemiology	1,000	
CDC	Natural History/Children Born to HIV-infected Mothers	Research	Epidemiology/Nat His	470	530
NICHD	Natural History of HIV Infection in Hemophilic Children	Research	Epidemiology/Nat His	0	800
CDC	Hemophiliac Children	Research	Epidemiology/Nat His	600	
CDC	Seroprevalence of HIV in Children in NYC/DC/Miami	Research	Epidemiology/Sero	0	308
NICHD	Seroepidemiologic Prevalence Study	Research	Epidemiology/Sero	200	1,250
NICHD	HIV Serosurveillance in Alabama Women	Research	Epidemiology/Sero	207	0
NIAID	Maternal Seroprevalence/NICHD	Research	Epidemiology/Sero	0	1,245
NICHD	HIV Screening of Newborns in Spain	Research	Epidemiology/Sero	0	250
CDC	Serosurveillance of Women of Child-Bearing Age	Research	Epidemiology/Sero	7,000	8,500
CDC	Hetero Trans/Transfusion-Associated Infection	Research	Epidemiology/Trans	0	493
ADAMHA	HIV Transmission in Newborns/Study in Pregnant Women	Research	Epidemiology/Trans	56	62
NIAID	Natural History of Perinatal Transmission	Research	Epidemiology/Trans	0	1,341
ADAMHA	HIV Transmission in Newborns/Study in Pregnant Women	Research	Epidemiology/Trans	131	146
CDC	Transmission Of HIV Mother/Child	Research	Epidemiology/Trans	1,087	1,974
ADAMHA	AIDS Associated Retrovirus Infection in Children	Research	Immunology	76	82
NICHD	Sperm-Lymphocyte Interaction Structures	Research	Immunology	105	130
NICHD	I:Gene/Transgene Regulation in Developing Mouse	Research	Immunology	400	3,000
NICHD	Culture Conditions that Promote Embryogenesis	Research	Immunology	30	100
NICHD	Immunoregulatory Factor in the Testis	Research	Immunology	27	0
NICHD	I:Biochem Basis of T Cell Activation	Research	Immunology	201	75

Agency	Project Title	Category	Functional Category	Funding 87 ($000s)	Funding 88 ($000s)
NICHD	Cullular Immune Mechanism in Infertility/Mouse Model	Research	Immunology	106	114
ADAMHA	Immunologic Function/Infants/Drug Addicted Mothers	Research	Immunology	168	175
NICHD	I:MuLV Sys Probe Replicative Pathways	Research	Immunology	40	0
NICHD	Studies of Human Choriogonadotropin	Research	Immunology	112	1,383
NICHD	I:T Cell Antigen Rec/Strm Bulsyn & Cell Biology	Research	Immunology	89	130
NICHD	I:Prevent Neuronal Deficits Associated with AIDS	Research	Prevention	66	100
NICHD	Data Center for Hemophiliac Study	Research	Research Support	0	225
NICHD	Support for Multicenter Mother/Infant AIDS Study	Research	Research Support	0	1,362
NICHD	Data Archive on Sexual Behavior/Contraception/STDS/AIDS	Research	Research Support	0	150
NICHD	Animal Model/HIV Trans/Barrier Contrac/Spermicides	Research	Simian AIDS	240	500
NICHD	Prophylactic Use of IV Gamma Globulin in Children	Research	Treatment	283	1,500
NIAID	Phase I,II and III Clinical Trials	Research	Treatment	0	4,133
NCI	Pediatric AIDS Inhouse Trials	Research	Treatment	850	1,120
NICHD	Significance of DNA Polymerases in Epididymal Semen	Research	Virology	86	0
NICHD	I:HIV Related Problems	Research	Virology	61	1,205
Total Research				**18,655**	**43,312**
FDA	No Specific Pediatric Activities/Funding Share Listed			360	
HCFA	Estimated Pediatric Medicaid Costs			10,000	14,000
Unclassified				**10,360**	**14,000**
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	49	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	65	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	405	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	39	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	110	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	155	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	68	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	202	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	40	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	70	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	85	

Agency	Project Title	Category	Functional Category	Funding 87 ($000s)	Funding 88 ($000s)
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	227	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	22	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	227	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	279	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	896	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	120	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	190	
HRSA	Hemophilia and Pediatric AIDS	Service	Delivery	168	
HDS	Social Service Block Grant	Service	Delivery	250	1,500
HRSA	Sprans-Networking/Community Services	Service	Delivery	400	
HRSA	AIDS Service Demonstration	Service	Demonstration	353	407
HRSA	AIDS Service Demonstration	Service	Demonstration	878	0
0HRSA	AIDS Service Demonstration	Service	Demonstration	200	0
HRSA	AIDS Service Demonstration	Service	Demonstration	200	0
HRSA	AIDS Service Demonstration	Service	Demonstration	315	332
HRSA	AIDS Service Demonstration	Service	Demonstration	711	724
HRSA	AIDS Service Demonstration	Service	Demonstration	401	399
HRSA	AIDS Service Demonstration	Service	Demonstration	273	411
HRSA	AIDS Service Demonstration	Service	Demonstration	2,971	2,701
HRSA	Pediatric AIDS Health Demonstration Project	Service	Demonstration	0	4,300
ASPE	AIDS Children and Child Welfare	Service	Research	80	0
ASPE	AIDS Children in Foster Care	Service	Research	0	135
CDC	Family Members of Hemophiliacs	Service	Research	200	
Total Service Related				**10,646**	**10,909**
TOTAL				**53,677**	**98,043**

Source: Submissions of the various workgroup agency representatives. All totals are estimates.