

WORK GROUP RECOMMENDATIONS

INTRODUCTION TO WORK GROUPS

The participants invited to the Workshop were assigned to ten Work Groups composed of approximately twenty persons. Group members were selected to reflect a broad range of background, expertise, and diversity of opinion. The Planning Committee provided the leaders and recorders in advance a set of charges herein summarized as "Definition of the Issues." With these issues as a starting point, the groups met in closed session for ten hours over a two-day period. Discussion was spirited. In most instances, consensus about current knowledge was reached, and recommendations were made for future action.

In a closing plenary session each group leader presented a summary of the group's deliberations to the Surgeon General. A condensation of these follows under "Response of the Work Group." The Surgeon General responded to these presentations in the conference's final hour.

WORK GROUP I: NATURAL HISTORY OF PEDIATRIC HIV INFECTION, INCLUDING DEVELOPMENTAL ISSUES AND PROGNOSIS

DEFINITION OF THE ISSUES:

The clinical presentations of HIV infection in children and infants, whether acquired perinatally or from blood or blood products, are quite variable. As a result, there has been inadequate definition and classification of the clinical course and prognosis, particularly with relation to differentiation of AIDS-Related-Complex (ARC) and progression to Acquired Immunodeficiency Syndrome (AIDS), Central Nervous System (CNS) disease, and death. Populations followed at different centers vary in terms of socio-economic background, clinical presentation, and medical management.

RESPONSE OF THE WORK GROUP:

The mechanisms of transmission of HIV from mother to offspring are unknown. Intrauterine transmission is well-documented, but the time at which intrauterine transmission occurs, the importance of evidence of additional maternal infection, the factors which influence risk of transmission, and the factors that

modify outcome of transmission are not understood. Available data to date have not shown a clear correlation between clinical status of the mother and the effect of HIV exposure to the infant. Some observations suggest that mothers in the late stages of AIDS may not infect their infants to the same degree as mothers who are asymptomatic or less severely involved.

In general, infants who are symptomatic early in life following intrauterine infection or from infection after transfusions in the neonatal period will have more devastating courses than those children who are asymptomatic in early infancy or those who acquire their infection through later transfusion or through administration of blood factors.

Laboratory abnormalities in pediatric HIV infection are now well recognized, but their significance in prognostic terms will be determined only through prospective longitudinal study. B-cell dysfunction may appear early and is associated with hypergammaglobulinemia. The development of lymphopenia, hypogammaglobulinemia, T-cell mitogen abnormalities, depression of both T4 and T8 cells, and loss of antibody to P24 (core antigen) suggest disease progression and probably are poor prognostic signs. In addition, there is a group of patients who are seronegative but have positive cultures; the significance of these findings is unclear.

Developmental issues are a major concern in pediatric HIV infection. Patterns include the infants who fail to progress in normal developmental sequence and those who develop normally initially but then either reach a plateau or deteriorate with loss of milestones. Primary CNS infection due to direct HIV invasion occurs in children as in adults. It can be difficult to distinguish the cause of developmental delay which may be secondary to sociocultural factors or recurrent opportunistic infections or from primary invasion of the CNS.

Whereas much has been learned about the clinical manifestations of HIV in infants and children, our knowledge is biased toward the common and severe expressions of the infection. Broad based study is required to obtain wider perspective.

RECOMMENDATIONS:

1) Long-term, controlled, prospective collaborative studies of the natural history of HIV, including assessment of clinical course and laboratory findings in children, are required now as a basis for development of effective means for prevention, diagnosis, and treatment. Appropriate government funding agencies should assist and even require development of common and shared protocols. Studies should include, but not be limited to: a) the roles of co-factors such as Epstein-Barr virus and other herpes viruses; b) strain differences in HIV and their relationship to clinical manifestations; c) distinctions between lymphoproliferative and lymphoablative disease with opportunistic infection; d) the prognostic significance of low incidence complications in pediatric HIV, such as cryptosporidiosis, *Mycobacterium avium-intracellulare*, and Kaposi's sarcoma; e) analysis of cerebrospinal fluid, including specific antibodies, cell mediated immunity, and antigens; and f) the roles of psychosocial and nutritional factors in the underprivileged populations which are at highest risk.

2) Denominator data are essential. Mandatory screening of all newborns is *not* recommended. Instead, limited screening studies, building on the existing neonatal screening programs for metabolic disease and sickle cell disease, should be implemented to help define the geographic seroprevalence of HIV infection.

3) Programs should be funded to explore ways to provide broad prenatal and neonatal testing for identification of HIV infected individuals. The programs should be initiated with sensitivity to the special dimension of HIV infection, especially regarding privacy and informed consent issues.

4) High priority should be given to development and evaluation of laboratory tests for identification of HIV infection in newborn and young infants. Particular attention should be given to longitudinal study of cerebrospinal fluid. The special vulnerability of the newborn, the irreversibility of brain damage caused by HIV, and the potential for benefit from early treatment (including the treatment of the asymptomatic HIV infected infant), give urgency to the need for sensitive, specific, and practical tests.

5) The CDC classification of pediatric HIV infection should be used to insure that all children with HIV infection are eligible for needed services not limited by statutory or regulatory definitions of AIDS. Continual updating of the classification can result in a useful transition document for education of health professionals and the general public about HIV infection.

6) Study of pathologic specimens from pregnant women and from children with HIV infection can make major contributions to understanding the natural history. These studies should include specimens of placenta, chorionic villi, products of conception, amniotic fluid, and cervical secretions. Professional education programs, based on existing successful models, should be created to assist in obtaining and studying such specimens. Consultational assistance by authoritative pathologists and clinicians should be included as part of the program.

7) Adolescence is a time of special hazard, but can be the focus of special opportunity for prevention of HIV infection. Recognizing the complexity of this problem, we recommend the prompt convening of a group to focus on the specific problems of HIV infection in adolescents.

WORK GROUP II: THE TREATMENT OF CHILDREN WITH HIV INFECTION

DEFINITION OF THE ISSUES:

The status of medical therapies for HIV infection, their indications and timing, their complications, and their sequellae are unclear. A number of drugs have been proposed for use in various stages of HIV infection, but their indications have not been developed for pediatric cases. The current therapies for secondary infections, such as pneumocystosis, cryptosporidiosis, and atypical mycobacterial disease, are generally unsatisfactory. Appropriate indications, dosages, and timing of antibiotics and gamma globulin need to be defined. Newer therapies, such as immunomodulators, may eventually have a place in pediatric management. Mean-

while, HIV infected children, though often immunosuppressed, will face the usual pediatric problems of immunization against childhood diseases and management of viral infections such as varicella and measles.

RESPONSE OF THE WORK GROUP:

It is imperative to determine the most beneficial therapies for children with HIV infection carefully and as quickly as possible. Children have the right to participate and must be included in therapeutic trials, so that appropriate treatment can be offered them.

There must be formed a well-funded, single collaborative pediatric treatment group, using the existing AIDS treatment and evaluation units as a foundation and incorporating the pending clinical studies groups. Our group recommends the designation of an executive director to assure efficient and rapid formulation of well-designed protocols for optimum utilization in the known HIV pediatric population. Our group also suggests that a commitment of a minimum of 12 million dollars annually to pediatric AIDS therapy is necessary for implementation of these recommendations.

Protocols for collaborative controlled Phase II trials of drugs such as azidothymidine (AZT) and ribavirin (Virazole) in children with AIDS must be ready for initiation as soon as the pharmacokinetic data from the current Phase I studies become available. Placebo-controlled trials in HIV-infected children with AIDS-Related-Complex (ARC) and in asymptomatic children must be designed in parallel with the above studies and implemented when appropriate data have accrued. The collaborative group also should begin now to design treatment trials in seropositive pregnant women and of infants born of such pregnancies to attempt prevention or, at least, intervention in the course of perinatally acquired infection. Natural history data and carefully evaluated diagnostic tests will facilitate the implementation of such studies.

RECOMMENDATIONS:

1) A controlled trial of intravenous gamma globulin therapy in conjunction with specific anti-HIV therapy would be useful but should not be done at the expense of decreasing available patient populations for the more important specific anti-HIV trials.

2) At a later time, specific use of immunomodulators in conjunction with specific antiviral therapy can be considered, but available data suggest a low priority currently.

3) *Pneumocystis carinii* pneumonia (PCP) is currently treated with trimethoprim-sulfamethoxazole and/or pentamidine. Evaluation is needed of aerosolized pentamidine, newer agents of the dihydrofolate reductase antagonist class, and of prophylactic therapy.

4) Lymphoid interstitial pneumonia (LIP) is a major problem. Combined therapy with steroids and specific antiviral agents needs evaluation.

5) *Candida* infections, including esophagitis, require systemic therapies, including amphotericin and imidazoles.

6) Cytomegalic virus (CMV) infections are difficult to manage, but new acyclovir analogs (gancyclovir) warrant Phase I and II evaluation. Children who are HIV-positive but CMV-negative should receive CMV-negative blood if transfusion is indicated.

7) Cryptosporidiosis and atypical mycobacterial infections are relatively infrequent in children. No effective therapy currently exists for them. Efforts should be directed toward finding treatment.

8) We support the current Advisory Committee of Immunization Practices (ACIP) recommendations for immunization of HIV-positive children. The use of age-appropriate inactivated antigens, such as DPT, pneumococcal, Hemophilus influenzae B, and influenza, is potentially beneficial in those HIV-positive children capable of responding to the antigens. These are without harmful effects. Administration of attenuated measles vaccine is recommended for asymptomatic HIV-positive children. It appears to be without hazard in this group of patients and may provide protection against wild measles virus, which is potentially lethal. Symptomatic HIV-positive children should not receive live virus vaccines. HIV-positive children exposed to measles should receive gamma globulin. Those exposed to varicella should receive varicella zoster immune globulin.

9) Management of HIV-infected patients with varicella should include acyclovir therapy. Patients with varicella, measles, and respiratory syncytial virus infections are extremely susceptible to bacterial superinfections, such as pneumonia and sepsis.

10) Indiscriminate use of antibiotics should be discouraged, but well planned studies of antibiotic prophylaxis would be helpful.

11) Nutrition and growth must be monitored carefully. Enteral tube feeding and total parenteral nutrition must be maintained appropriately. Irradiated blood, if available, should be administered when indicated.

12) There is a pressing need for experienced pediatric subspecialists to care for these children. We strongly support the training of these individuals.

WORK GROUP III: RISK REDUCTION FOR MATERNAL/FETAL TRANSMISSION

DEFINITION OF THE ISSUES:

The predominant paths of HIV infection transmission from mother to child are not understood. The effect of pregnancy on the health of the infected mother is uncertain, as are the effects of the infection on the outcome of pregnancy.

Eighty percent of American children with AIDS are of black or Hispanic parentage. Their mothers are predominantly of lower socioeconomic status, and most often are intravenous drug abusers or sexual partners of men in high-risk categories. Counseling of HIV-infected women, when achievable, must consider these factors and center on understanding the risk of pregnancy, birth control methods, informing sex partners, and issues of confidentiality. There are no satisfactory guidelines for HIV antibody testing of women of child-bearing age with known risk factors.

RESPONSE OF THE WORK GROUP:

We define these general points as background to our recommendations.

a) In a series of "life-points," each offers opportunities for education and risk reduction. Some of these occur during adolescence or even earlier, some at the time of premarital and family planning counseling, and some during pre-conceptual, antepartum, intrapartum and postpartum care.

b) The concept of "parental-fetal" transmission (rather than "maternal-fetal") emphasizes the role of the male partner in infecting the mother and through her, the fetus.

c) Adolescents are an especially important target group for risk reduction efforts. There is a need to design relevant approaches to them, perhaps through the use of peers and/or popular role model adults.

d) It is important to stress that transmission to the fetus is currently very strongly linked to inner-city, disadvantaged, minority populations. The connection between poverty, intravenous drug abuse, and heterosexual transmission leading to fetal infection underscores the importance of a massive effort against the primary problem of substance abuse.

e) The young, drug-addicted, infected prostitute is more at risk for pregnancy and fetal infection. North American evidence of transmission of HIV from prostitutes to "Johns" to their other sexual partners and from bisexual men to heterosexual females needs to be determined by thorough epidemiologic investigations.

RECOMMENDATIONS:

1) There should be a vigorous expansion of HIV-antibody testing, always within a context of confidentiality, voluntary informed consent, and pre- and post-test counseling. The group sees no current role for mandatory testing or screening under any circumstances, but counseling and testing should be routinely offered to all pregnant women as early in pregnancy as possible. For those who have negative tests, testing should be offered again late in the third trimester, at least three months after initial testing to allow for important pediatric management and follow-up.

2) Risk assessment and access to counseling and testing should be widely available at such points as family planning clinics, sexually transmitted disease clinics, abortion clinics, drug treatment clinics, and at all health care centers for women and their sex partners. Major funding investments are urgently needed for counseling resources, and health professionals must take a much more active and knowledgeable role.

3) HIV infection status should be part of the medical record. The group was divided as to whether test results should be in the generally available chart. Strict confidentiality must be observed, but the information must be available for appropriate obstetrical and pediatric care. Maternal HIV status is relevant to newborn care and ideally should be discussed in confidential consultation between physicians, especially obstetricians and pediatricians. Strong legislative protection of confidentiality and against discrimination is urgently needed on a State-by-State basis, and the possibility of Federal legislation should be examined. Expanded AIDS education is needed by all members of the health-care team.

4) With regard to antibody test outcomes: a) presentation of test results, whether negative or positive, should be accompanied by counseling regarding

risk-avoidance; b) the seropositive pregnant woman should be provided information on the full range of risks to herself and to her offspring, should have access to the full spectrum of options (including termination of pregnancy) in a nonjudgmental, noncoercive context, and should receive the support of health care providers if she decides to continue her pregnancy; and c) the seropositive non-pregnant woman should be advised to defer pregnancy. There should be sensitivity to the difficulties faced by many women in avoiding pregnancy.

5) Although definitive evidence for HIV transmission through breast milk has been lacking, the documented presence of HIV, both within lymphocytes and in cell-free breast milk, suggests that it is prudent to advise seropositive women not to breastfeed, especially in North America, where formula feeding is a safe alternative. Donors of breast milk should be screened for HIV infection.

6) Available risk-reduction modalities, such as use of condoms and use of sterile syringes and needles for intravenous substance abusers, must be made more easily accessible.

7) Sperm donated to sperm banks for artificial insemination should be made as safe as blood donated to blood banks by mandating statutory requirements for collection and freezing of the sperm.

8) Mandatory premarital HIV antibody testing would not be appropriate and would probably be ineffective in reducing HIV infection. However, premarital risk assessment, counseling, and voluntary testing should be encouraged.

WORK GROUP IV: EDUCATIONAL ISSUES FOR CHILDREN ALREADY INFECTED WITH HIV, INCLUDING DAY CARE AND SCHOOLING

DEFINITION OF THE ISSUES:

Much confusion and fear cloud the issue of the safest and most effective means of educating the HIV-infected child. The consternation accompanying association with HIV-infected individuals is perhaps most marked with the enrollment of an infected child in day-care centers and schools. Proper education, confidentiality, and safety for infected children—particularly those who are immunosuppressed—and their non-infected schoolmates must be considered. School boards, school principals and directors, teachers, and families need sensible, realistic guidelines based on the best current knowledge. Resources must be developed for dissemination and implementation of new information as reported.

RESPONSE OF THE WORK GROUP:

Education of the HIV-infected child should be geared to developmental age. We considered those under age five as preschoolers and also distinguished toddlers from three- and four-year-olds. Positive messages about education should be based on known epidemiology and stage of disease. There are children known to be HIV-infected yet asymptomatic, those with unrecognized infection, and those ill with HIV and dying. All of these may be attending school or may be rejected from school if their medical history were known.

RECOMMENDATIONS:

1) There is no evidence that HIV is transmitted by normal casual and nonsexual contact in home, school, day care, or foster care settings. Screening of children for the presence of HIV antibodies for the purpose of attendance at day care centers or school is neither warranted nor recommended. Routine common sense procedures for handling blood and body fluids should be adopted for everyone. The decision to inform others of HIV infection should only be made with the consent of the parent and/or guardian. Although it is ideal that someone in day care or school know that a child is ill, that should not be a prerequisite for attendance and may not be practical at this time in many communities.

2) Existing Centers for Disease Control (CDC) and American Academy of Pediatrics (AAP) guidelines are well done and serve as an adequate resource in most respects. However, the group recommends the following modifications:

a) If infected toddlers can safely mingle with peers, that should be so stated. If there is evidence they can transmit HIV infection to each other, that evidence must be clearly presented. We have not seen any data that toddlers can transmit HIV infection. CDC comments on the preschool population are somewhat ambiguous. CDC should reanalyze data or design new studies if existing data cannot be brought to support clearer recommendations one way or the other.

b) We do not agree with the Academy's suggestion that an expert panel review toddler admissions to day care. The child's own physician and parents can make a reasonable decision. Community school boards and departments of health may make a panel available if physicians, parents, or teachers request expert advice. The child does have the right of privacy. Doctors should share data on HIV infection with others only upon careful consideration of likely community reaction and with parental consent. This right to privacy extends to a child attending preschool or day care.

3) The following are our suggested criteria for admission to school. For children of developmental age three years and up, there is no need for special school admission criteria. HIV-infected children should be permitted to attend school unless prevented from doing so by weakness or poor health. For preschoolers less than age three and for older children developmentally less than an age three equivalent, we suggest a more positive national position. Hedging at the national level may lead to fear at the local level. Again, CDC should reexamine the accumulated data and either make a more positive statement or quickly gather data about transmission between toddlers.

4) Under ideal circumstances, the teacher or someone in the school should know the diagnosis and be an active participant in the team caring for the child. In many communities, however, it may not be possible for the child to attend school in an unrestricted manner if the diagnosis is known. The child has the

right, therefore, to have the information withheld from the school. The decision as to whether an immunocompromised child can attend school safely, with the unavoidable exposures to enteric and respiratory ailments, is best left to his own physician and caretaker. Schools need to notify all parents about outbreaks of illnesses such as measles and varicella, which pose a particular threat to immunocompromised children.

5) Whenever possible, school systems should be prepared ahead of time by education of staff, parents, and social workers, to accept an HIV-infected child should one be identified. Current hygienic measures are sufficient in most school and preschool settings, and handwashing facilities always should be accessible. If soap and water are sufficient to clear up blood spills, this should be stated in published guidelines which currently tend to emphasize the need for bleach. Positive hygienic measures should be clearly stated and adhered to consistently.

6) Children with HIV infection should share the same curricula as their uninfected schoolmates, including age-appropriate health and sex education. Counseling regarding sexual behavior for HIV-infected adolescents should focus on risk reduction and modes of transmission. There must be age-appropriate education about AIDS for all children: common sense information about body functions in preschool years; counseling about decision making and developing self esteem in elementary school; specifics about risk reduction and transmission before the age when a child begins to experiment with sex and drugs.

7) Use of the antibody test in children must be done with prudence and for reasonable clinical cause. The group opposes mandatory testing prior to school attendance.

8) Ultimately, it should become possible for AIDS to be considered with neither more nor less emotion than other severe illnesses of infancy and childhood. Key issues of AIDS epidemiology are poorly understood by most segments of society. A concerted community educational effort should be undertaken. Guidance and education programs developed with Federal support should be directed from national groups to their memberships, including health-care groups, education and parent groups, and social work groups.

WORK GROUP V: THE ROLES OF EPIDEMIOLOGY AND TRANSMISSION STUDIES IN THE ADVANCEMENT OF KNOWLEDGE OF PEDIATRIC HIV INFECTION

DEFINITION OF THE ISSUES:

The incidence of congenital HIV transmission is closely related to the spread of HIV infection among intravenous drug users and their sexual partners, partners of bisexual men, and—to an increasing degree—among the heterosexual population. Other children at risk include: neonates, those with blood dyscrasias who have received multiple transfusions, hemophiliacs managed with blood products, children with cardiac anomalies repaired by surgical by-pass, and sexually abused children. The routes involving vertical (adult-to-child) transmission need proper quantification. Further studies are needed to provide information and projections about the course of the epidemic.

RESPONSE OF THE WORK GROUP:

The current national reporting of pediatric AIDS is only a very small reflection of the total problem of HIV infection in infants and children.

The current annual number and distribution of HIV-infected women and HIV-infected infants can be estimated by utilizing available data from area-specific HIV antibody surveys and by extrapolating from reported AIDS cases in adult females. Such estimates in early 1987 placed the number of HIV-infected women at about 100,000. About 70% of these were from minority groups in New York, New Jersey, and Florida, with 80% of the infections attributed to intravenous drug use by the infected woman or her sexual partner. By applying published age, race, and specific fertility rates to this estimate, we calculated that about 3,000 HIV-infected infants may be born annually in the United States. The number of both infected women and their infants can be expected to increase over the next several years. However, accurate projections of the rate of increase are not possible at this time because of major uncertainties in key variables.

Studies in Massachusetts and New York show prevalence of HIV antibody in pregnant women ranging from 2% up to 6%. The Massachusetts Department of Health has developed an anonymous, confidential screening test using blood specimens collected on filter paper for newborn metabolic screening. Patient identification was removed, but race and general geographic area were retained. Testing of these specimens provided valuable data on the general prevalence and distribution of HIV-infected women giving birth and their infants. Other States should consider inaugurating this method so that intensive follow-up and educational programs can be targeted to the high prevalence areas.

RECOMMENDATIONS:

- 1) The majority of our group felt that mandatory premarital testing would not be effective, but that voluntary testing, with pre- and post-test counseling, should be offered at family planning clinics, sexually transmitted disease clinics, and drug abuse treatment programs.

2) Insufficient data are available to indicate what proportion of infants may be infected in utero or at birth, and what maternal factors may be important for transmission of HIV infection to the offspring. The group recommends convening a meeting of those investigators involved in current or prospective studies of HIV-infected pregnant women to develop additional protocols to answer important questions regarding maternal-fetal transmission.

3) With respect to the possibility of infection by an HIV-infected toddler to other toddlers in a day care setting, we conclude that if such a transmission risk exists at all, it would be an exceedingly low one, and that such a non-risk or low risk would be difficult if not impossible to measure by a prospective epidemiologic study. However, guidelines and a specific protocol should be developed by CDC to direct a public health investigation when such is warranted.

4) Donors of breast milk should be screened in a manner similar to donors of either blood or body organs. When environmental circumstances are such that withholding breast milk might be associated with a known increased risk of morbidity and mortality, breast milk should not be withheld even though there may be potential incremental risk of HIV transmission from an infected mother to her infant.

5) The risk of HIV transmission through blood transfusion in the period before screening (specifically between 1979 and 1985) appears low enough that routine recall for testing of children who received blood appears unnecessary. We concur, however, with the recent CDC recommendations that screening based on geographic areas and number of units received may be appropriate.

6) HIV testing should not be done routinely on all children admitted to health care facilities, but it should be performed when there are specific clinical and epidemiologic indications to suspect HIV infections. Protocols for evaluation of a child who has been sexually abused should consider the possibility of HIV transmission.

7) The collection and interpretation of epidemiologic and transmission studies must be sensitive to different ethnic and cultural groups. The press and general public must understand that the nature of scientific studies prevent public officials from implying that an "unlikely" event will "never" occur.

WORK GROUP VI: FAMILY ISSUES, INCLUDING COUNSELING AND PSYCHOSOCIAL ISSUES

DEFINITION OF THE ISSUES:

The potential for stigmatization complicates the health and social care of the HIV-infected individual at any age. In particular, school-aged children with HIV infection become the focus of fears of teachers, classmates, and neighbors. The result may be ostracism, discrimination, and low self-esteem. Many of these children are already the victims of drug-abusing parents, paternal bisexuality, and low socioeconomic status. About 15%, however, became HIV infected by

receiving HIV contaminated blood or blood products. Many will not survive to school age. Counseling of the children and the families of these differing subsets of patients must necessarily be adapted to the circumstances. Counseling must aim at providing psychosocial support for families, discussing pregnancy risk, and reducing high-risk behavior. The demography and social dynamics of HIV infection should be studied thoroughly to develop effective means of reaching people at risk, to delineate the obstacles to behavioral change, and to determine an effective language and style of communication.

RECOMMENDATIONS:

1) We suggest that a continuum of services be assured to all affected communities by the Federal government, working through State and community facilities. These services must range from fundamental necessities, such as food, shelter, transportation, and mainstream education to the critical needs for emotional and other psychosocial support services. We believe that it is a Federal responsibility to provide a structure for leadership and funding for local planning and program development. The organization, development, and implementation of psychosocial services must be considered of equal importance to medical services with a corresponding allocation of funds.

2) Direct services to families with HIV-infected children should be planned, organized, and implemented by a community-based, child-centered multidisciplinary team, consisting of representation from health and social service specialties, augmented by community service representatives and family members. Services should be geared to family assessment in its own ethnic and cultural context with consideration for its religious orientation and spiritual needs.

3) Throughout the process of working with a family affected by pediatric AIDS, a consistent counseling relationship establishing respect and mutual trust must be maintained. Professionals must be aware of and sensitive to cultural issues, sexual and reproductive mores, and psychosocial aspects of drug abuse. Psychosocial personnel must be recruited from appropriate minority groups with bilingual counseling available as needed. All involved Federal and State agencies should establish training of involved personnel as an immediate priority.

4) We urge expanded access to drug treatment services and increased funding for such services to improve quality and to remove financial barriers.

5) It is essential that families have a clear understanding of proposed medical and social interventions given in their own language, and that they be afforded the opportunity for a truly informed consent. Although family involvement should and must be encouraged, adolescents must be provided the opportunity to obtain services independent of parental knowledge and consent.

6) It is critical that minority representation be included at policy-making levels. We recommend that the Surgeon General take the lead in providing a forum of prominent black and Hispanic/Latino leaders, especially physicians, to be heard on a national level.

7) Planning for research in the areas of psychosocial interventions, health care service delivery, and services evaluation should include local community representation, with the Federal government assuming a leadership role in the dissemination of acquired information.

8) CDC should revise guidelines on education and foster care and on perinatal transmission to incorporate the psychosocial, cultural, and ethnic factors discussed above.

9) Cultural, racial, ethnic, gender, and psychosocial issues should be specifically addressed at all future national conferences on HIV infection, as they have been at this one. This is necessary for a broadening of the understanding and communication of all professionals working in the field.

WORK GROUP VII: HEALTH INFORMATION ISSUES AND THE ROLE OF THE MEDIA

DEFINITION OF THE ISSUES:

The standard print and electronic public media, in concert with profit and non-profit health information services, are the means by which information about AIDS is disseminated to the general population. The media must both receive and transmit accurate information in a responsible manner. This information must reflect, but not be confined to, current knowledge and epidemiology, natural history, transmission of the disease by mother to child or by blood and blood products, treatment, and research in the development of drugs and vaccines. Even more important, the media are essential for the dissemination of information to minimize the spread of the disease, including modifications in life style, the understanding of high-risk sexual behavior, and the risks of pregnancy for the HIV-infected mother. Such preventive information must be adapted to reach those cultural, ethnic, and social groups most at risk. Methods should be developed for evaluating the effects of health information systems on public knowledge and habits.

RESPONSE OF THE WORK GROUP:

The group felt that there are certain specific steps that would improve the effectiveness of communication regarding HIV infections and AIDS. First, it was felt to be essential that ambiguities and imprecision be avoided in terminology and jargon. Meaningless euphemisms, such as "the exchange of bodily fluids," should be abandoned in favor of clear and explicit language.

Because journalism has unique responsibilities differing from other forms of mass communication, we have developed separate recommendations for the news media. The professional journalists on our panel felt it inappropriate for them to make policy recommendations about subjects which they cover.

RECOMMENDATIONS:

1) Current information campaigns often seem to define risk for AIDS by membership in specific groups, rather than by high-risk behavior. This approach serves to increase stigmatization and discrimination and undermines the public's understanding of health risks. We urge the government to take the lead in helping to reverse this trend.

2) A panel independent of government and consisting of journalists and other authorities in the communication field should be convened under the aegis of a group such as the National Academy of Sciences or the Institute of Medicine. The panel should include individuals with expertise in communicating with those target segments of the population for which AIDS is a particular concern. A media resource guide should be developed by such a panel. This should include, but not be limited to, such AIDS information sources as research scientists, government agencies, legal and civil rights organizations, social service organizations, and health care associations. Data bases, such as the Scientists' Institute for Public Information (SIPI) or the Computerized AIDS Information Network (CAIN), are particularly valuable.

3) This panel should stimulate the development of a style book to address the use of ambiguous ("sexually active"), judgmental ("promiscuous"), or stigmatizing ("innocent victims") language. The publications of the panel should be distributed widely to journalists and to other communicators.

4) The panel also should explore the issues of confidentiality in reporting of AIDS. These issues must include the needs of journalists for information, the public's right to know, the right to privacy for persons with AIDS, and the responsibilities of health care providers and social service workers to serve the needs of their patients and clients.

5) Significant portions of the population, including intravenous drug users, adolescents, those with language barriers, some homosexuals, and poorer individuals, are not being reached with the educational messages that are conveyed through traditional media. The techniques of market research should be used to identify the most effective means of communicating with all parts of the population, and alternative communication resources should be explored for the dissemination of information about AIDS. These should include direct mail, explicit television public service announcements or educational spots, posters on busses and subways and at rock concerts, comic books, as well as the integration of information concerning AIDS and responsible sexual practices into all television programs, including entertainment. Messages should be targeted for specific publics, with recognition of linguistic, cultural, societal, and age differences.

6) Specifically, the public and private sector should work in concert to:

a) translate public information programs into appropriate languages, such as Spanish;

b) improve communication with the black community by assembling an advisory group of black leaders from the community, the clergy, health providers, and the media;

c) urge Hispanic/Latino leaders of the medical profession and electronic media to take the lead in the education of their communities;

d) enlist black and Hispanic/Latino opinion leaders and role models to deliver educational messages through appropriate mass media; and

e) disseminate information about HIV risk to intravenous drug users through urban community and outreach programs.

WORK GROUP VIII: MODEL FOR HEALTH CARE OF CHILDREN WITH HIV INFECTION, INCLUDING BOTH IN- AND OUT-OF-HOSPITAL CARE

DEFINITION OF THE ISSUES:

The disadvantaged and underserved children most at risk for HIV infection are also at greater risk for many other diseases and conditions. Their health care is typically fragmented, episodic, crisis-oriented, and underfinanced. They usually are denied a relationship with a primary physician who might assume responsibility and accountability for their health. Their care is often complicated by parental intravenous drug abuse, parental HIV-related infection, homelessness, and abandonment. There is a lack of foster-care placements, resulting in prolonged stays in hospitals, where there is insufficient staff to provide and coordinate multidisciplinary attention. Pediatric units in hospitals that serve large numbers of HIV-infected individuals are overwhelmed by the medical and social needs of ill and potentially ill HIV-infected children. Programs which provide coordinated, community-based care and hospice environment for pediatric HIV-infected patients are nearly non-existent.

RESPONSE OF THE WORK GROUP:

The development of a model of health care for HIV-infected children demands that we, who are responsible for their care, face the complexities of poverty, its resultant social disorganization, and the attendant hopelessness. Pediatric HIV infection is commonly related either directly or indirectly to intravenous drug use. Because the resources for the prevention and treatment of drug abuse are insufficient to meet the needs of this country, we encourage everything possible to expand treatment and prevention programs dealing with drug abuse.

RECOMMENDATIONS:

- 1) The Department of Health and Human Services (DHHS) should initiate efforts to simplify access to existing health, welfare, social, and financial services for HIV-infected children and their families.
- 2) Whenever possible, these children should remain with their own families. The provision of social and medical supports—including but not limited to housing, home care, and respite care—will help preserve, as much as possible, the family unit and reduce the need for foster care. Existing systems for handicapped or disabled children must be made accessible to HIV-infected children.
- 3) When care of the child within the family is not possible, individual foster care represents the best possible alternative. We suggest increased foster care funding, along with additional social and practical supports such as day care and home care, in order to recruit larger numbers of badly needed foster parents.
- 4) The recommendations for increased supports for the natural family, or if not possible, for the increased recruitment of foster families will not successfully provide care for all HIV-infected children. Innovative nurturing homes for small numbers of HIV-infected children should be established. In these community-based homes, children would be cared for by appropriately trained and super-

vised caregivers who will bond with and care for the children and, if possible, their parents.

5) Regionalized, comprehensive medical care programs tailored to regional needs should be instituted. These should use a multidisciplinary team approach to provide primary care for HIV-infected children. Services should be provided with a greater emphasis on location of patients rather than on location of traditional tertiary care services. Obviously this model will have to be tailored to individual regions, but must include attention to the education of local health care providers about clinical and social needs of HIV-infected children and their families. At the medical level, these children need a pediatrician with the instincts of a primary care provider and a broad perspective. They must also have highly trained nurses and social workers to facilitate, negotiate, and coordinate services for them.

6) We recommend that health care providers and Federal, State, and local policy makers enlist the local minority leaders and community organizations in the development and implementation of programs for HIV-infected children. Such cooperation is necessary as we develop a national strategy.

7) In those sections of the nation with either little or no pediatric AIDS now, community, government, and professional leaders in health, public health, and human services should begin immediately to plan for the care of the HIV-infected children who will inevitably appear in the near future.

Certain metropolitan centers have increasingly large numbers of antibody-positive infants, many of whom do not have homes to which they can be sent. Hence these recommendations have an urgency ignored only at our peril. Over the last six years, all of us have been forced to deal with problems perhaps better appreciated by health professionals of 50 years ago, but unknown to us since the advent of antibiotics. There is much we do not understand about this disease, but we do have enough knowledge to treat these children and their families so that the quality of their lives is improved. Since many children afflicted with AIDS are poor, it is our responsibility to ensure that they receive the medical and social care they need to live humane and civilized lives. It is our moral obligation to do so.

WORK GROUP IX: FINANCIAL ISSUES IN THE CARE OF CHILDREN WITH HIV INFECTION

DEFINITION OF THE ISSUES:

The AIDS epidemic will impose incredible economic burdens at the international, national, State, local, and family levels. In many areas, hospitals, blood banks, and local governmental and social service agencies already are being strained financially. Methods have to be found for accumulating data, raising sufficient funds, and developing channels for support for all aspects of prevention

and treatment of pediatric AIDS. We must take into account the increasing number of cases, the need for increased prevention programs, and inflation. The peculiarly pediatric issue of abandoned HIV-infected babies must be considered. Suggestions for protocols and legislation for cohesive programs must be outlined to allow governmental and quasi-governmental agencies, foundations and other non-profit organizations, third-party payers, hospitals, corporations, families, and individuals to promote cooperative economic strategies.

RESPONSE OF THE WORK GROUP:

While the increased funding for research and education in response to the AIDS epidemic is to be applauded and encouraged, we need to pay more attention to financing the delivery of treatment and related social services for those already infected and those who may become ill.

RECOMMENDATIONS:

1) Because reliable data are scarce, we can make only rough estimates of the health care costs of pediatric HIV infection. Given the limitations of the current surveillance definition of AIDS and the underreporting, a projection of 10,000 pediatric cases with symptomatic HIV infection by 1991 seems probable. A number of studies has found hospital utilization of 30 to 40 days per year per child. For those children who cannot be discharged because of extraordinary placement and care problems, the figures are much higher. We estimate that by 1991 between 800 and 1,000 hospital beds, representing 2% of the nation's pediatric beds, may be needed. The impact will be much greater in the high-prevalence areas for pediatric AIDS, such as Newark, New York City, and Miami. Obviously, there are also other costs, including drugs, home care, ambulatory services, and foster care. The care must be multidisciplinary and must involve thorough coordination across a wide range of services and settings.

2) Our financing strategies must be designed to support and encourage alternatives to hospital care whenever possible. We cite two examples:

New Jersey is the first State to develop a "Home and Community Based Services Model Waiver for Persons with AIDS/ARC" under the Medicaid program. Under this waiver, New Jersey has elected to provide services such as foster care, case management in a community-based setting, private duty nursing, medical day care, personal care assistance supervised by a registered nurse, and drug abuse treatment. This brings Federal matching dollars into the State for multidisciplinary services not normally covered under Medicaid.

In New York State, designated AIDS Care Centers receive an increased reimbursement rate for enhanced care to AIDS patients. The goals of the program are to improve the patients' quality of life and to reduce in-patient care through maximum utilization of ambulatory services. Some of these facilities include specific pediatric AIDS services providing family support and linkages with community programs. The program has an evaluation and financial data collection component.

3) AIDS often strikes those with the least ability to pay and may affect entire families. Many of the required services are not covered by either public programs or private insurance. Approved drugs, like AZT, may cost \$10,000 per patient per year and often are not covered by private or public programs. Some changes

in our current method of financing health care clearly are needed. The recommendations of our group are based on the idea that all segments of the health care financing system should share the cost of HIV-related illness.

4) We support legislation which would waive the 24-month disability waiting period for Medicare eligibility for patients with AIDS who often do not live long enough to qualify.

5) For most of the children with HIV infection, the primary health coverage is through Medicaid. We recommend that the Federal government add critically needed services to the minimum benefits which States are required to provide. Specifically, approved drugs, foster care, and home nursing care should be required of all States under Medicaid, with matching Federal funds. The Medicaid waiver program should be expanded to all States, along the lines of the New Jersey pilot program. The private sector should be encouraged to join these waiver programs by contributing funds for the development of case management and out-patient services and by developing innovative coverage strategies.

6) A large number of families of the working poor and the uninsured will fall outside the scope of these coverages. The income eligibility requirements for Medicaid should be altered to allow these families to be covered. As the number of pediatric HIV infections increases, the private sector will have to become more involved, and the Federal government must assume a greater share of the cost of care.

7) A national commission on AIDS, as proposed in pending Congressional legislation, could consider strategies for development of catastrophic health care coverage and would allow for improved accumulation of data better to project future expenses.

WORK GROUP X: EDUCATION AND BEHAVIOR MODIFICATION TO PREVENT HIV INFECTION

DEFINITION OF THE ISSUES:

The issues of how and when to teach children about sex and drug abuse have been with us for decades. We must now add a third issue of when and how to teach about HIV infection and its relationship to sex and drugs. The spread of the AIDS epidemic adds a sense of urgency and fresh controversy to these concerns. The questions are what, when, where, and how to teach children of different age, social, and ethnic backgrounds an understanding of high-risk sexual behavior, the avoidance of drugs, and the prevention of HIV infection.

RECOMMENDATIONS:

The main goal of an AIDS prevention program is to prevent, modify, or eliminate behaviors which may place our children and youth at risk for acquisition of HIV infection. Our recommendations are as follows:

1) A nation-wide, multi-dimensional AIDS Prevention Campaign must be developed and implemented, with adolescents and youth as the targeted group. Specifically, it should include:

a) a social marketing campaign to promote the acceptance and use of condoms as a method of disease prevention. This campaign shall include promotional advertising aimed at all socioeconomic and ethnic groups, as well as steps to increase the availability of condoms to all economic sectors, including free distribution and/or price subsidies;

b) a direct mailing to every household in the nation with a straightforward AIDS prevention message; and

c) the convening of a meeting of innovators in business, advertising, entertainment, and publishing to develop agreement with national leaders to promote AIDS prevention messages through a wide variety of outlets. These include active advertiser support of programs that provide information about risk exposure and transmission from the standpoints of both sexual practices and drug abuse. Sexual abstinence should be portrayed as the preferred method of AIDS prevention. Sexually active people should be presented as caring and responsible adults in their use of condoms to prevent AIDS.

2) A separate office of the Chief of AIDS Operations should be established under the Secretary of Health and headed by an official of national stature with staff and funds commensurate to the importance of AIDS.

3) To be effective, education and prevention strategies must be modified to conform to cultural patterns and beliefs. Information from existing studies on cultural behavior, beliefs, and practices should be examined and incorporated into AIDS prevention strategy. Members of identified cultural communities should be involved in all phases of program planning and implementation.

4) Community-based programs, directed to adults who influence youth and to youths themselves, lend themselves to the development of creative approaches for education. Mechanisms should include educating legislators and other policy-makers and utilizing resources directed to reach youth—including peer groups, hotlines, and newsletters—with the coordination and consultation of the youths themselves. Knowledgeable professionals should be trained and their services made available through national organizations.

5) Clergy and denominational leaders should accept responsibility for creating and disseminating material that describes the disease of AIDS, leads to its understanding and control, and provides acceptance and comfort to infected individuals.

6) The Surgeon General should facilitate development of a model HIV infection prevention curriculum with age-appropriate components for pre-kindergarten through college-age students and include teacher-training materials. Schools should place immediate emphasis on education from the junior high through college level, and resources should be developed for counseling students at highest risk. Community-based programs should be integrated with the school educational material. Longer-term school plans should add AIDS prevention education to all school health programs, including health services, clinics, health education classes, and counseling.

7) All AIDS prevention education, whether in-school or out-of-school, should contain two components: a) information and b) skill development. Skills should include communication and coping skills, assertiveness training, self-esteem development, and decision making. We hope the program would help youths to develop a sufficient sense of themselves to postpone intercourse, refuse drug use,

avert sexual abuse, and effectively insist on the use of condoms when becoming sexually active.

8) We recommend Federal, State, and community sponsored programs specifically directed to youth at high risk for HIV exposure: gay and bisexual teenagers, pregnant young women, juvenile male and female prostitutes, runaways, incarcerated youth, and homeless or socially disenfranchised young people. Immediate attention should be directed to the geographic areas of highest HIV prevalence.

9) The current drug avoidance campaign must be expanded to teach intravenous drug users avoidance of AIDS risk. Outreach programs must stress how to avoid drug use and how to gain access to drug treatment programs. Individuals who can't or won't refrain must be taught to avoid sharing needles, how to obtain and use clean needles, and at a minimum how to clean quickly and effectively previously used needles with bleach or alcohol. The communication must be simple, visual, multilingual, and culturally directed.

10) Often, counseling on a repetitive basis is needed to encourage and help maintain behavioral changes. Effective school-community programs must contain the capability for individual and group counseling by experienced professionals.

11) All components of the HIV prevention campaign should include testing and evaluation of implementation, process, and outcome by scientifically designed studies using valid measurement tools.

RESPONSE OF THE SURGEON GENERAL

As Surgeon General, I have neither the power nor the money to implement all of the recommendations of the work groups. I am a catalyst, and my power is that of moral persuasion.

Perhaps the most moving moment of this Workshop came when Mrs. Kushnick said that she was told the death of her son would not count as AIDS. We hope that Mrs. Kushnick and her family recognize how much their courage and their work has made Samuel's life and struggle count very much indeed. We feel that our work here should be dedicated to all the infants and children who—like Samuel—were struck down by pediatric AIDS before we ever recognized the disease. Our work here can begin to help all of the parents and all of the Samuels in the world.

Now I want to respond to the various recommendations of the work groups. Questions about the CDC definition of AIDS are recurrent and are intermingled with questions about and seeming inconsistencies in the numbers of cases of AIDS and the various subcategories created by factors such as age, sex, ethnic group, and presumptive mode of acquisition. The basic confusion comes from the difference between the clinical diagnosis of AIDS (which is made by a physician and is based on clinical acumen and laboratory tests) and the epidemiologic surveillance methods developed and used by CDC. It is absolutely vital to develop accurate methods for both. The ability to diagnose improves with the increase in both our knowledge and our diagnostic tools. To be useful for revealing trends in transmission and incidence as well as for predictions about the future, the CDC definition of AIDS requires consistency. The criteria for inclusion in CDC reporting have changed in the past and will change again as our information becomes more complete. In any case, we should all be careful to make a distinction between clinical diagnosis and epidemiologic reporting.

I acknowledge the recommendations about the CDC guidelines and also those of the American Academy of Pediatrics, and I thank the work groups for doing such a thorough, critical job. I will see that the leadership of both CDC and AAP are promptly made aware of your recommendations.

Certainly, the recommendations of the group working on the natural history of AIDS in children emphasize the importance of comparable longitudinal studies of the disease and its various forms of progression. We expect that the new clinical classification of AIDS published in the *Morbidity and Mortality Weekly Report* (MMWR) will be useful in these efforts and also in the development of multicenter studies of various therapeutic interventions.

The concrete suggestions for research efforts on both the course of the disease and on the treatment protocols of various agents such as ribavirin and AZT will be taken under consideration. In reference to longitudinal studies and information gathering, I can report that Dr. Virginia Anderson, a Public Health Service officer and a participant in this Workshop, has already been detailed by the Service to the Armed Forces Institute of Pathology where she is responsible for a pediatric AIDS registry. I will see that she receives the mailing list of this Workshop in order that she may inform the participants about the registry and how it works.

We are grateful that you have emphasized our ignorance about AIDS in adolescents. The CDC definition of pediatric AIDS ends at age 13; perhaps we have not given sufficient attention to this vulnerable group. We know that 139 teenage cases have been reported. In the *Surgeon General's Report* of October 1986, I did say that adolescents may not know if they are homosexual or will be drug abusers and therefore might not heed or understand messages others might find pertinent. These youngsters must be reached and taught about risk behaviors that expose them to infection with the AIDS virus. We need to know how this virus affects youth during this second period of rapid growth.

We also take note of the specific legal and ethical concerns of drug trials in infants, children, and youth; we are pleased that you have delineated these concerns for us.

Special note is made that many of the children may actually be under the guardianship of a local child welfare agency. We need to help these agencies understand more about pediatric AIDS. This understanding is necessary for the provision of the extra supports these children need and for the awareness of risks and benefits of various treatment protocols. The New Jersey program demonstrates that such a program can be successful.

We should recognize that AIDS can be a possible consequence of child abuse, as some centers dedicated to this problem are already aware. Later this week I will be having the second meeting of a group called "The Health Law Initiative." This is a joint project of the Attorney General and the Surgeon General. We are writing national guidelines which will outline the principles of care for victims of child abuse and their families. The guidelines will also include legal principles relevant to collecting evidence. I will see that the Workshop recommendations are included in those guidelines.

We agree that pilot studies should begin in order to learn the most efficacious methods of newborn detection, including examination of cord blood, careful assessment and follow-up of the newborn, and laboratory distinction between maternal and infant antibodies.

We also agree that the implications of breastmilk transmission are likely to be more critical in developing countries. One cautions that information about AIDS should not cause reduction of breastfeeding when we are attempting to encourage breastfeeding in general. I will bear your strictures in mind, especially when I represent you as delegate to the World Health Organization in the first two weeks of May. I expect this topic will be a part of the heated debate at that time, in view of the past history of that organization over breastmilk substitutes.

Work groups III and V also presented some specific epidemiologic directions for studies by both CDC and National Institutes of Health (NIH). The National Institute for Drug Abuse can be especially useful in providing the knowledge of the connections between the drug-using population and those who work with them. NIDA knows the networks of drug-treatment programs. This knowledge can shed light on the problem of how transmission occurs, how pregnancy affects the woman with HIV infection, and what is the frequency of infected offspring. We acknowledge, however, that studies about drug usage should not be confined to the methadone clinic population—likely to be a biased sample. Of highest priority also is to inform both public and professionals about the outreach programs for drug users in New York, New Jersey, and other States. These programs are successful in improving knowledge and modifying behavior of drug users. Such programs create an immediate need for adequate treatment and prevention programs for addicts, and we must increase the number of slots available.

We believe that women at risk should receive care at a well qualified center before they become pregnant, and an infected woman—and later, her infant—should have the benefit of care by those most experienced. This care should be provided in a regionalized system most suited to the need of each community. The Health Resources and Services Administration (HRSA) has begun to assist four cities in their plans for care for all with HIV infection, and more such projects will be funded this year. These plans include the care of women and children. You advised us that plans must include care in and out of hospital, including counseling and education, psychological support services, foster care, day care, and child development. The suggestion that nurturing homes for small numbers of children be established has struck a responsive chord and is accepted. I will seek to bring together the Division of Maternal and Child Health, the Office of Human Development Services, and the Health Care Financing Administration (HCFA) to pursue this innovative idea.

We have all seen examples of children and youth, as well as siblings and other family members, barred from essential services because of the stigma of AIDS. We have brought participants to this Workshop who could tell us how to be successful in overcoming these barriers and in providing needed services and access for these families. Your recommendations are rich with suggestions we will try to implement. Some of these accommodations are for the public sector, some for the private sector, some for a partnership between the two. I will bring these sectors together to review your recommendations.

For those of you from the various communication media who have developed your Work Group's statements, I hope you note the enormous restraint I have imposed upon myself in answering you. I accept your statements at face value, and I am delighted that you emphasized the need for both clarification and precise, explicit words. During this Workshop, we have heard how many different meanings there are for the same words or phrase. I have long been aware of the problem of semantics in reference to AIDS, and if I have offended anyone, I apologize. Throughout my involvement with AIDS, I have chosen my words about this topic carefully. In spite of the headlines, I have never used the words "safe sex" or "safer sex" and I never used the words "school-based clinic." These buzz words mean very different things to different people. Sometimes I deliberately use words that may seem offensive to some because I am trying to attract the attention of others. For example, when I use the words "innocent victim," it is not to indicate that others are not innocent. It is meant to attract attention, especially of those in our society who would consign all persons with AIDS to outer darkness. I use the term "high risk" because at-risk groups asked me to use it.

I see no reason why we cannot bring together the kinds of people you suggest to write a glossary of terms, not only for the medical profession, but also for the media. We must first achieve consensus before we achieve uniformity, and I will try to catalyze this process.

A project for reaching minority leaders is already underway, and I hope we can announce its effect before very long.

The Surgeon General's Report of October 1986 has already been translated into Spanish and will appear soon. Camera-ready copies will be available for those who wish to reprint the report in Hispanic newspapers or magazines. The Report of this Surgeon General's Workshop will also be printed in Spanish.

We agree that AIDS information should be disseminated by family planning clinics. We already have AIDS Information Programs in all of the ten regions

of the Public Health Service through family planning activities in clinics supported directly or indirectly by PHS funds. We will expand these efforts to the best of our ability.

Catastrophic insurance is something that has always been near to my heart, since I dealt with the tremendously overburdening problems of surgical difficulties in the newborn for over thirty-five years in this very Children's Hospital. Several decades ago, I thought catastrophic insurance was needed for youngsters. As a matter of fact, the very first talk I ever gave in Washington in reference to my present career was on catastrophic insurance for pediatric patients.

With reference to church groups, I have had a cordial reception from all the Protestant groups I have been working with since the first of the year. I have been particularly pleased with the reaction of the National Association of Religious Broadcasters. I spoke to 3,000 of them in Washington last February, and although I chastised them, their response was warm. The most important thing is that many of them who reach a large segment of the radio and television audience are transmitting a message to their constituencies concerning sexuality and concerning the problem of AIDS. One Roman Catholic experiment in Dallas is outstanding. The diocese assembled a curriculum for their junior high and middle school. As I understand it, they gave the courses after school and invited students from the public schools as well. My further information is that the classes were well attended.

The recommendations given by the work group on education are worthy, but difficult to carry out as presented. In the Federal government, we are constantly reminded that we are not in the retail business of education. We do have some model curricula, however. One of those is already a pilot study in Indiana. Other programs from CDC will serve as models to be copied in the days ahead.

Since this past January, I have tried to draw attention to the need for discussion among Federal, State, and municipal health officials and political figures and the private sector to do three things: 1) to assess the cost of AIDS on an annual basis in the future and to consider how the money will be raised, what it will be used for, and who will make that decision; 2) to consider the role of insurance in the cost factors of AIDS; and 3) to plan for alternative types of care for the terminally ill AIDS patient. With the importance of this pediatric workshop, I will stop calling for such actions and will try to effect them as soon as possible.

In the *Surgeon General's Report* of October 1986, I called upon communities to set up task forces to anticipate every phase of community life and of the social fabric impacted by the AIDS epidemic. Many sections of the nation have not yet encountered the problem of pediatric AIDS. In these States, governmental and professional leaders in medicine, public health, education, and human services must begin immediately to plan for what they are going to do when their cities do have a number of HIV-infected children. I will facilitate this process by providing appropriate consultation through our well established network of State, Territorial, and municipal health offices as soon as possible.

Recommendations from this Workshop will be printed in a report within three months. We will ask each of you to inform the Office of the Surgeon General during the next two years about progress on today's recommendations. We have followed this protocol with other workshops, and it has been very successful. We will share subsequent information with all of you so that you will know how your colleagues have fared. You can profit from their successes (or mistakes). We anticipate a follow-up report at the end of two years. The Workshop Report

and all future material will go to every group with potential to respond to your recommendations.

I would like to tell all of you how much I appreciate your presence here. I am sure it is not my gratitude that you seek, but rather—through today's efforts—the gratitude of children yet unborn.