AIDS programs should enlist the assistance of credible and respected opinion leaders and organizations, recognizing that these leaders and organizations may differ from those that are credible to other populations.

Future Challenges

The issues raised at the Charlottesville meeting present at least three challenges to the PHS regarding minority communities. First, PHS is challenged to apply the experience and information developed in addressing AIDS to overcome other diseases in minority populations. Second, PHS is challenged to use the experience gained in addressing these overarching issues in the minority community to benefit society in general. Third, PHS is challenged to foster an ongoing partnership among cooperating PHS, State, and local government units and minority community-based organizations and institutions.

Pediatric AIDS

Background and Progress

The acquired immunodeficiency syndrome was not recognized in children until well after its initial description in adults. Initially it was difficult to distinguish AIDS from other rare congenital immunodeficiency diseases in children, but several researchers convincingly demonstrated that the human immunodeficiency virus affects the pediatric as well as the adult population. Infants and children can be infected by donor blood and blood products as well as via transmission from their infected mothers.

Of the more than 74,000 cases of AIDS reported to the CDC as of late September 1988, 1,185 were in infants and children under 13 years of age at the time of diagnosis, and 300 were adolescents 13 through 19 years of age. More than half of those in the 0 through 12 age group (672) were known to have died.

The PHS predicts an increase of almost 300 percent in pediatric AIDS, to 3,000 cases, by 1991. This estimate reflects only those children with AIDS who have been reported to CDC. It does not include other infected children who are either asymptomatic, or symptomatic at any of the earlier stages of disease. It is likely that every child who meets the 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 U.S.

Minority children, many of whom face urban poverty, poor health, lack of access to adequate health care, and educational disadvantages, comprise the majority of pediatric AIDS cases. While black children constitute 15 percent of the total U.S. child population, they represent 53 percent of all childhood AIDS cases; Hispanic children are 10 percent of the U.S. child population and represent 23 percent of all childhood AIDS cases.

Nationally, the number of infants and children with AIDS from birth though age 12 represent between 1 percent and 2 percent of all AIDS cases. In some metropolitan areas, however, the percentage of pediatric AIDS cases may be as high as 4 percent of the total AIDS cases--a variation that reflects a correlation between perinatal transmission of HIV and the number of adult drug users who are infected with HIV. Recent studies demonstrate that HIV seropositivity has reached alarming levels among childbearing women in some major cities. For example, a New York Health Department study conducted in November 1987 indicates that one out of every 61 babies born in New York City is born to a woman infected with HIV.

Evidence suggests that HIV is transmitted from infected mothers to their infants *in utero* by transplacental passage of the virus; during labor and delivery through exposure to infected maternal blood and/or vaginal secretions; and, although infrequently reported, postnatally through breast feeding. The remainder of infants and children have been infected primarily through blood transfusions or use of blood products. Most of the cases of AIDS in adolescents reported to date were the result of contaminated blood products used in the treatment of hemophilia. An increasing number of adolescents, however, are becoming infected through sexual contact or intravenous drug abuse.

Approximately 100,000 women of childbearing age in the U.S. are estimated to be infected with HIV. Many of these women are identified as infected only after their children are diagnosed as having HIV infection, including AIDS. It is not uncommon for HIV-infected women to have several pregnancies before becoming clinically ill.

Between 30 percent and 50 percent of the infants born to HIV-infected mothers are themselves infected with HIV. However, it is difficult to deter-

mine whether an infant born to an infected mother is truly infected, since both infected and uninfected infants acquire AIDS antibodies from their mothers during gestation, and current tests cannot distinguish between passively transferred maternal antibody and antibody the child generates against infection. Because this passively transferred antibody can persist in children for as long as 15 months, a positive antibody test by itself is not diagnostic of HIV infection in perinatally exposed children under 15 months of age.

Pediatric HIV disease including AIDS differs from the disease in adults in a variety of ways. Children with AIDS often develop severe bacterial infections, and a large proportion have mental or motor retardation. The natural history of the disease is not only different in children, it is less well understood than in adults. Moreover, AIDS progresses very differently in different children. Most of the children reported with perinatally acquired AIDS (87 percent) had met the CDC case definition for AIDS before their third birthday, while 3 percent were diagnosed after their sixth birthday.

Infected infants and children who receive comprehensive health care have markedly fewer hospitalizations and experience an improved quality of life. Early results of drug treatment with AZT for children with HIV appear to be promising, as is the use of intravenous gamma globulin to reduce bacterial infection.

Relatively few of the country's 25 million adolescents aged 13 to 19 have been identified as having AIDS, but the prevalence of HIV infection in this age group is unknown. More than half of adolescent AIDS patients are of minority origin, and the ratio of diagnosed male to female cases is 6:1 (as opposed to 12:1 in adults). The proportion due to heterosexual transmission is 8 percent, twice that for adults.

While only 1 percent of all AIDS cases are diagnosed in adolescents, 4 percent of all AIDS cases are diagnosed in men and women between 20 and 24 years of age, and 21 percent in persons between 20 and 29. Because the virus can have a long latency period, it is likely that many of these young adults were infected as adolescents. Many aspects of the lifestyles of adolescents and young adults in the U.S. put them at serious risk for HIV infection.

The cost of providing a full range of services for the pediatric population with AIDS is expected to be high, reflecting the fact that these youngsters require long periods of costly inpatient care. Comprehensive ambulatory care and community-based services could considerably reduce in-hospital occupancy and its attendant costs.

Among the high priority issues to be addressed are supportive services for families of HIV-infected persons, including--in addition to health and social supports--home care, day care, and respite care. Systems for developmental evaluation and care of handicapped or disabled children should also be accessible to HIV-infected children. When care for the child within the family is not possible, foster care is the best alternative and should be accompanied by these same services. Group homes for small numbers of HIV-infected infants and children may be necessary as transitional housing or, in communities with large numbers of HIV-infected children, as long-term care. Tracking may be a useful public health measure for known asymptomatic seropositive mothers and infants (for instance, to provide these women with contraceptive counseling), with case management as needed.

Children with AIDS have a particular dependency--in many cases, virtually total dependency--on the community and on government. This unique dependency arises from the complexity of their health care needs and the high costs of treatment, the stigma that they often face, the fragility of their families, and the poverty into which they are so often born. Individuals, communities, and government all need to respond.

Research has only begun to formulate the questions to be addressed. We are in the earliest stages of our knowledge about the epidemiology, pathogenesis, natural history, clinical manifestations, and treatment of this disease in children and in their mothers.

This cross-cutting report examines the issues addressed by each workgroup with regard to pediatrics and some other relevant issues not mentioned in the individual reports, but thought to be important to the field.

Epidemiology and Surveillance

Most issues relating to HIV epidemiology and surveillance are equally relevant for both pediatric and adult populations. Estimates of the prevalence of HIV infection have been made, but time delays between diagnosis and reporting of data do not permit very precise estimates in either pediatric or adult populations. Additional natural history and other data are needed before these estimates can be substantially improved.

With specific reference to pediatric HIV disease, a panel of pediatric health care consultants from various disciplines should review the usefulness of the pediatric AIDS case definition and HIV classification system for identifying serious HIV-related illnesses in children under 13, and explore the feasibility and practicality of establishing a national pediatric HIV reporting system through State and local health departments.

Emphasis must also be given to developing the descriptive epidemiology of pediatric HIV infection including the prevalence, incidence, clinical spectrum, and natural history of infection in all affected groups--perinatally-infected, blood/blood component-infected, and sexually-transmitted. The factors that mitigate the evolution of significant morbidity and symptomatology and the early predictors of disease progress should be elucidated.

Prevention

A comprehensive risk-reduction program that includes information, education, counseling, and testing is needed, especially among high-risk groups such as adolescents and drug abusers, and to prevent perinatal transmission.

Emphasis must be given to research on the motivations for risk-taking behavior which includes unprotected sexual activity and drug use, on the determinants of high-risk behavior, and on the determinants of maintaining low-risk behavior.

The workgroup recommended national, state, and local AIDS prevention strategies specifically to reach children and youth, both in and out of school, including those who are incarcerated, in the military, working, or not in an institution/organization with an education program (e.g., runaways). In the case of children and youth in schools, teachers in all schools should be encouraged to implement and evaluate comprehensive school health education on AIDS.

Pathogenesis and Clinical Manifestations

Because the current inability of clinicians to diagnose HIV infection reliably and early in infants born to infected mothers may slow the development of therapy for newborns, considerable emphasis should be given to the development of reliable diagnostic technology for this age group. The workgroup noted that knowledge about the pathogenesis, natural history, and clinical manifestations of pediatric HIV disease is limited. Research is needed into the modes and timing of transmission of HIV from mother to infant. Studies of the fetal and placental tissues of HIV-infected women are necessary, and the role of breast milk in the transmission of HIV must be examined. The prevalence of HIV infection in all age groups must be determined, and the variability of the natural history of HIV infection in all pediatric age groups, including adolescents, as well as in pregnant women and women of childbearing age, must be studied. The nature and scope of disease manifestations in pediatric HIV infection (including neurologic, renal, embryopathic, pulmonary, and cardiac) need to be examined, and a more encompassing clinical classification system of pediatric HIV infection needs to be developed. Both diagnostic and prognostic indicators (laboratory and clinical) should also be developed.

Therapeutics

Recognizing both the special biological and social characteristics of the HIV-infected pediatric population, this workgroup strongly emphasized the special needs of the children infected via so-called perinatal or vertical transmission. It specifically recommended that all HIV-infected children, regardless of social or economic circumstances, should have access to clinical trials of agents against this disease. A comprehensive system of care should be developed, at first to conduct clinical trials and later to develop and evaluate models of care for HIV-infected pediatric patients. Barriers that may limit children's access to clinical trials now and to state-of-the-art care later should be addressed. Adolescents, with their special needs, must be included in this comprehensive care system, which has clinical therapeutic research at its core. This comprehensive care system should also accommodate those newborns whose disease status is indeterminate, as well as asymptomatic infected children, infected pregnant women, and infected women of reproductive capability.

Maternal and pediatric HIV disease raise certain legal and ethical issues. These include: (1) the role of placebo-controlled drug trials in HIV-infected children, and (2) universal screening of pregnant women and/or neonates.

Blood and Blood Products

The workgroup recommended additional protection for the Nation's blood supply, a better descrip-

tion of the natural history of HIV infection and HIV disease in hemophiliacs and transfusion recipients who received infected blood and blood products, and an assessment of problems related to the care of hemophiliac patients. These recommendations apply to children and adolescents as well as to adults. It is essential that all ongoing studies of transfusion-related and blood products-related HIV infection (e.g., "look-back," longitudinal followup studies) be examined to ensure that all age groups are represented. Studies addressing the development of blood-borne HIV disease in the pediatric population should be pursued. The risk of progression to symptomatic HIV disease including AIDS and the manifestations of blood-acquired HIV disease must be examined and understood in all age groups.

In addition to addressing these research questions, it is also important to assess and study the service and care needs for HIV-infected children who acquired their disease via blood and blood products. It must be determined if and how these needs are being met and, if they are not, address ways to begin to meet these needs.

Intravenous Drug Abuse

Because most perinatally acquired AIDS cases are directly or indirectly a result of illegal intravenous drug use, education and intervention efforts are needed to reach IV drug abusers and induce them to reduce drug use and also alter sexual activities that may lead to pediatric AIDS cases. Specifically, counseling programs should be designed for women at risk for both HIV infection and pregnancy; women who are HIV positive should be encouraged to use contraceptives and avoid pregnancy. Continuing services should also be provided to high-risk women through outreach programs, with special attention given to adolescents. IV drug abuse programs should target the special needs of minority women, pregnant women, and young people.

There is special concern about IV drug abusers in their role as parents. Children with AIDS often have a parent, typically the mother, who is also a patient. Her needs are varied and include social and emotional support as well as medical care. The accessibility of obstetrician-gynecologists as well as psychologists and social workers may be essential not only to her care, but also to her role as caregiver to the pediatric AIDS patient. When the parent(s) are unable to be the caregiver, another family member may be able to step in. Procedures should take into account the child's need for family support and facilitate it when it does exist.

Neuroscience and Behavior

The workgroup noted the substantial neurologic morbidity that is prevalent in HIV-infected children. There is a need for research that addresses the issue of the neurovirulence of HIV and related retroviral infections, and the mechanisms of invasion and destruction of the nervous system in the development of neuropsychiatric disease pre- and postnatally in children and in adolescents. It is also clear that there is a need for longitudinal, controlled, prospective studies to delineate the natural history and the effects of HIV infection on the developing central nervous system of prenatally or perinatally infected infants. Careful attention must be given to the development of measures of cognitive, emotional, and psychomotor function that are adequate (both culturally and educationally), sensitive, and specific.

Some of the HIV-infected children who survive (long-term or short-term) can be expected to be developmentally impaired. The special care needed by these children must be addressed; effective interventions to maximize their potential must be identified and made accessible to them.

Because the large majority of HIV-infected children were born to mothers who were directly or indirectly infected through drug use, behavioral strategies are needed to increase the likelihood that women recognize their risk for infection, choose counseling and testing, avoid pregnancy if seropositive, comply with drug treatment if needed, and get adequate prenatal care if pregnant.

Patient Care/Health Care Needs

To provide comprehensive care for infected children during the course of their HIV infection, currently available modalities should be expanded and new ones created. Strategies must be developed to provide for the health care needs of children who survive HIV disease, especially for the ones who will be developmentally disabled. Efforts should be made to begin to assess the community needs for services, facilities, and health personnel for the next five years. Special emphasis should be given to the development of family-centered care programs. Additionally, strategies should be developed that would help reduce the formal and informal barriers that prevent HIV-infected children

from entering school, child care, and other programs.