

Recommendations

Many of the specific Federal action steps that were recommended in the first ONAP report to the president on HIV and AIDS in America's youth (*see Attachment B*) have been taken over the last four years. This response required a serious commitment and is commendable.

However, two tragic realities have not changed. Some 20,000 young people are still becoming infected every year, and most of them are not receiving the medical care they need. The programs that provide HIV prevention, care and support services to youth must be broader in vision, larger in scope, and better coordinated. As pointed out by some of the recommendations that follow, there is certainly more to learn, but we know enough now to make a real difference if we work together.



The specific recommendations listed on the following pages begin to outline a plan of action.

These recommendations should be expanded into a three-year, comprehensive national plan

that addresses the full range of issues pertaining to HIV/AIDS in youth, with special emphasis on the needs of young people who are at highest risk of HIV infection. The national plan should identify gaps in our current response, and it should be updated on a regular basis. The President should designate a high-level point person to make sure that a National Youth HIV/AIDS Prevention Plan is developed, implemented, and kept up to date.

The Institute of Medicine (IOM) is conducting a comprehensive review of current HIV prevention efforts in the United States. Based on this review, the IOM has been charged with proposing a visionary framework for future national HIV prevention strategy. The IOM's final report, due in September, 2000, along with agency-specific plans that are in place or in progress, should be used to help inform a National Youth HIV/AIDS Plan that addresses prevention, research and care issues.

An effective plan will:

- ▶ be developed in consultation with all Federal agencies and offices responding to AIDS, as well as with young people, service providers, researchers, and advocates;
- ▶ create or reinforce strong linkages among Federal health and social service programs, such as STD, substance abuse, family planning, youth development programs; and
- ▶ provide a basis for future allocation of HIV prevention resources among and within Federal agencies.

PREVENTION RECOMMENDATIONS:

The Federal government should ensure that adequate resources are targeted to youth-focused HIV prevention, particularly prevention that targets youth at highest risk for HIV infection.

Although young people account for half of new HIV infections, less than a quarter of all HIV prevention program funding is directed towards this age group. Funding for in-school and out-of-school prevention programs that target high-risk youth is insufficient to halt the spread of HIV among young people in America.

- ▶ A substantial amount of new funding should be allocated for implementing the strategies identified in a National Youth HIV Prevention Plan.
- ▶ Federal agencies should use existing resources to expand youth-specific initiatives.
- ▶ All Federal funding for HIV prevention among young people should more equitably address the needs of youth at highest risk for HIV infection. They include youth of color, homeless and runaway youth, youth in other high-risk circumstances, youth who engage in substance abuse, and sexual minority youth.

High-quality HIV prevention programs should reach more youth in schools.

HIV prevention education has an optimal context—coordinated school health programs that speak to the full range of health issues affecting youth. These are issues such as nutrition, exercise, family planning, HIV and other STDs, injuries, and the use of tobacco and other substances.

Where there is scientific evidence that a unit on any of these issues is effective in promoting healthy behavior, use of that unit should be encouraged. Where there are no evidence-based units, development and evaluation of relevant curricula should be supported. Tools for education about other STDs should be developed further and made widely available. The HIV prevention component should definitely be evidence-based.

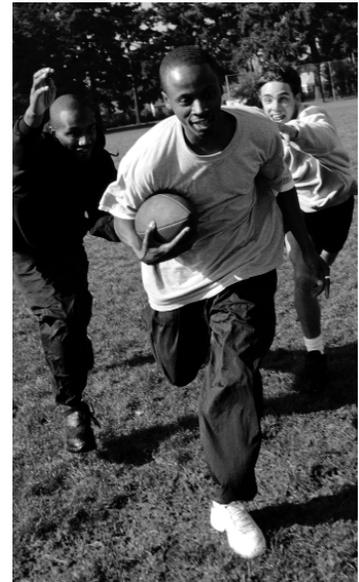


- ▶ CDC should do more to support and promote coordinated health education and evidence-based HIV prevention programs in the nation's 15,000 school districts.
- ▶ Schools and other prevention service providers should adhere to best practices as identified by prevention science, and those receiving new funding should be held strictly accountable for such adherence. A relatively large amount of Federal funding is currently dedicated to untested, abstinence-only programs. Priority for future funding increases should be given to programs with demonstrated effectiveness in decreasing behavioral risk of infection with HIV and other STDs, and of unintended pregnancy.

- ▶ Schools should increase and enhance the prevention services they provide to high-risk youth, consistent with priorities set by local community planning groups.

Community-based HIV prevention services for young people should be widely available, coordinated with other services, and user-friendly.

- ▶ Condoms should be made readily accessible to sexually active youth, and advertised in media that reach this target audience.
- ▶ CPGs should take additional steps to recruit and retain young people.
- ▶ CDC should expand training and support for collaboration among community planning groups, state and local education agencies, and other youth-serving organizations at the state and local levels. In addition, the National Youth HIV/AIDS Plan should include specific steps to improve coordination of youth prevention activities at the Federal level, both within CDC and across Federal agencies.
- ▶ The multiple systems and services that touch the lives of young people should integrate science-based HIV prevention into their ongoing activities. After-school programs, prevention programs that focus on issues other than HIV, church programs, programs for youth in the juvenile justice system, and one-on-one encounters with general practice healthcare providers are examples of resource-conserving opportunities for HIV prevention.
- ▶ As parts of a multi-pronged prevention strategy, STD education, screening and treatment, and drug abuse treatment should be supported at levels that make these services available to all young people who need them. Medicaid managed care contracts are one of the avenues that should be explored for expanding the availability of these services to young people who are eligible for Medicaid.



The Federal government should develop and implement an initiative to promote routine, voluntary HIV counseling and testing for at-risk youth.

The Federal government should mount an aggressive, multi-faceted campaign to promote voluntary HIV counseling and testing to youth who have engaged in HIV risk behaviors. The campaign should be at the scale of the remarkably successful public health effort to reduce HIV transmission from mother to child. The counseling and testing initiative should be a component of the National Youth HIV/AIDS Plan. It should build upon existing Federal initiatives to prevent HIV infection and promote HIV counseling and testing among at-risk populations.

Significant new resources will be necessary to fund this initiative. Its goals should be increasing the number of at-risk youth who seek HIV counseling and testing, increasing the number of HIV-positive youth who are diagnosed and linked to comprehensive care, and providing high-quality prevention services to at-risk youth whose test results are negative. As outcomes of this initiative:



- ▶ voluntary HIV counseling and testing should become a routine component of adolescent health care. For example, school health personnel should inquire about HIV risk behavior in the course of medical exams (e.g., those often required for playing sports) and offer HIV counseling and testing to youth who have engaged in risk behavior.
- ▶ HIV counseling and testing sites funded by CDC and HRSA should offer convenient, youth-friendly services to all youth at risk. The services should be designed to reflect the developmental and emotional needs, language and culture of young people.
- ▶ HIV testing sites and programs should have strong linkages to youth-friendly care and treatment facilities; and
- ▶ social marketing campaigns and other strategies should be used to encourage all at-risk youth to seek HIV counseling and testing.

The Federal government should encourage public/ private partnerships that address the full range of needs of high-risk youth.

High-risk youth need a variety of supportive services and continued contact over time with caring, knowledgeable service providers. Providing this level of support demands substantial resources, but there is no more worthwhile investment. Meeting the needs of our high-risk youth will take realism, creativity, and persistent hard work on the parts of families, communities, the private sector and government at all levels. Young people, parents, and other adults all have roles to play, but the Federal government must provide leadership and support for a coordinated effort.

- ▶ The report on adolescents in high-risk settings released by the National Research Council of the National Academy of Sciences should help guide the National Youth HIV/AIDS Plan.
- ▶ The President's point person on youth and HIV should identify categorical and other restrictions on Federal support for youth development programs (e.g., mentored volunteering) with evidence of lowering HIV risk behavior. Recommendations should then be made about when and how to remove barriers to public/private partnerships interested in resiliency-building approaches to meeting the needs of high-risk youth.
- ▶ There should be additional Federal support for the development and scientific evaluation of cooperative models of service that combine resources from the public and private sectors.

Increased support from the Federal government is needed for the development and dissemination of promising models of HIV prevention programs for youth.

- ▶ HHS agencies should redouble their current efforts to derive best practices from prevention science and local program experience, to disseminate this information to school boards, community planning groups, corporations, foundations and other decision makers, and to advocate for the adoption of effective HIV prevention models.
- ▶ The Federal government should find additional ways to help researchers and community-based HIV prevention service providers share information, and to help them work together.

CARE AND TREATMENT RECOMMENDATIONS

The Federal government should ensure that all HIV-infected youth have access to comprehensive, community-based health care and supportive services that address their medical and psychosocial needs.

- ▶ Under current policy, people become eligible for Medicaid when they receive an AIDS diagnosis. Congress should act to expand this eligibility to cover all low-income people living with HIV. This is particularly important for HIV-positive young adults over age 18 because they do not qualify for the SCHIP program.
- ▶ The Federal government and States should expand efforts to enroll youth who are currently eligible for SCHIP and Medicaid into these programs.
- ▶ The Federal government should find new avenues to provide health care coverage for uninsured adolescents and young adults who exceed current limits on age or income eligibility for Medicaid and SCHIP.

The Administration should build on the Ryan White CARE Act to deliver care to youth affected by HIV and AIDS. As it stands now, only a small percentage of Federal AIDS CARE Act resources target youth.

- ▶ Within Title I and Title II of the Ryan White CARE Act, funds should be set aside for youth just as they are currently set aside for other special populations. Funding of services for youth should, at a minimum, be proportional to the percentage of cases of HIV/AIDS that young people represent.
- ▶ Increased funding for the Ryan White CARE Act Title IV Adolescent Initiative could provide resources to communities that have significant populations of HIV-positive youth but are not currently funded under the initiative.
- ▶ New funds could support evaluation and quality assurance for Title IV Adolescent Initiative programs. Support for building permanent service links with substance abuse, mental health, family planning, and adolescent primary care programs should also be provided.



For youth living with HIV/AIDS, housing is an essential component of comprehensive care, but many at-risk and infected young people lack stable housing. Additional assistance will help provide housing, access to care and supportive services, and a stable base that helps make it possible to maintain adherence to often difficult medical and other therapeutic regimens.

- ▶ Funding for HOPWA should be expanded to serve the growing number of low-income persons who are living with HIV and AIDS and who need housing assistance, including families and youth.
- ▶ HUD should encourage state and local governments to undertake coordinated planning and service delivery in the areas of housing, health-care, mental health, substance abuse, skills training and other services that are relevant to the needs of at-risk and HIV-infected youth.

The Federal government should improve the quality of services for HIV-infected youth.

- ▶ The Federal government should provide additional funding for training and technical assistance programs to help HIV treatment and care providers respond to the unique developmental and psychosocial needs of young people living with HIV and AIDS.
- ▶ More health care providers could be recruited and trained specifically to treat young people with HIV. One possible recruitment approach would be to create incentives such as scholarships and loan repayment programs within the National Health Service Corps for health professionals who commit to working with adolescent HIV care programs.
- ▶ To respond to emerging issues in adolescent HIV care, HRSA could continue to fund a significant number of youth-focused projects within SPNS.

RESEARCH RECOMMENDATIONS

The Federal Government should ensure that its research agenda for HIV/AIDS includes a component targeted to youth.

Research related to HIV and youth is being conducted by a number of Federal agencies, and regular review of the entire portfolio could be valuable in identifying research gaps and setting priorities. The planning procedure instituted by the Office of AIDS Research (OAR) at NIH over the last several years is a possible model for this review.

- ▶ HHS should ensure that representatives from Federal agencies, researchers, youth service providers, advocates, and young people develop, regularly update, and carry out a comprehensive, coordinated Federal agenda for AIDS research

on adolescents and young adults. This agenda should address the full range of research related to physical and social development, epidemiology, prevention, supportive care, and treatment, and it should direct the allocation of youth AIDS research funds within and among Federal agencies.

- ▶ In addition, the OAR should designate a senior staff member to help coordinate youth-focused AIDS research activities at NIH. OAR should use its budgetary authority to increase youth-focused research and to help implement the Federal research agenda on youth and HIV/AIDS.

The Federal government should ensure that appropriate resources are targeted to adolescent-specific AIDS research.

Implementing a youth-focused HIV research agenda will require a greatly expanded adolescent research infrastructure. It should, in part, build on existing efforts such as the Adolescent Medicine HIV/AIDS Research Network, and should be developed in collaboration with existing research groups and other stakeholders.

More research support is needed to study topics such as:

- ▶ those identified by the Working Group to Review the NIH Perinatal, Pediatric and Adolescent HIV Research Priorities;
- ▶ surveillance of HIV infection rates and risk behaviors among youth;
- ▶ determinants of risk behaviors among youth of color, sexual minority youth, and youth in high risk circumstances (e.g., homeless and runaway youth);
- ▶ multi-level prevention strategies (e.g., those that reach young people through school, parents and media);
- ▶ comprehensive prevention programs for high-risk youth;
- ▶ ways to tailor existing, evidence-based prevention approaches to address the needs of specific racial/ethnic and risk groups within the broader population of young people;
- ▶ service planning, coordination, and cost effectiveness;
- ▶ policies and other structures that enhance the delivery of evidence-based prevention programs for youth, and ways to encourage the creation of these structures;
- ▶ care-seeking behavior;
- ▶ the level of unmet need for services for high-risk youth;
- ▶ barriers to youth participation in clinical trials; and
- ▶ treatment regimens for adolescents that are easy to follow.

Federal agencies conducting HIV/AIDS-relevant clinical trials should take action consistent with Federal rules and regulations on research with minors to increase youth participation in the trials.

- ▶ NIH should promote increased research participation by HIV-infected young people in clinical trials. The recruitment, enrollment and retention of youth in the Adult AIDS Clinical Trials Group, Pediatric AIDS Clinical Trials Group, Community Programs for Clinical Research on AIDS, and the networks that evaluate vaccines and other preventive interventions should be improved. It may be necessary to pay special attention to increasing the participation of youth of color. All NIH AIDS research sites should document steps they are taking to enhance youth participation in studies and to gather the opinions and counsel of young people regarding recruitment issues.
- ▶ NIH, HRSA, and other Federal agencies should ensure that health care providers who work with HIV-positive youth are better educated about opportunities for participation in AIDS research. They should also be made aware of effective strategies for promoting youth participation in research.



Immediate and useful dissemination of research findings to local communities must be considered a key part of the research agenda.

As discussed under the Prevention Recommendations heading, Federal agencies that conduct research on HIV and AIDS should coordinate and expand their efforts to translate research results into practice. At the other end of the dissemination pipeline, schools and local service providers should settle for no less than evidence-based approaches. Active, two-way communication mechanisms must be developed more fully.

Conclusion

“...we’re all worried about the choices our teenagers make... about how the best-laid plans for a bright future can be dashed with a single bad decision...”

*Hillary Rodham Clinton,
White House Conference on Raising
Responsible and Resourceful Youth*

A safe passage into a productive, rewarding adulthood—this is our dream for our children. But, as William Butler Yeats said, “in dreams begins responsibility.” Timid hopes for the best are not enough; families, businesses, communities, and government must join young people in realistic, vigorous action. Young people have a right to depend on us as adults. We must mobilize our nation’s resources—resources that are unparalleled in American history—to protect and care for them.

We cannot slip into complacency about matters that should inspire us to act. We must not forget that the HIV and AIDS statistics assembled in this report are not really about numbers but about real young people who are just starting their lives.

And we cannot ignore our obligation to learn what we can about HIV prevention and care for young people, and to share these lessons abroad. Our advances in prevention science, medical science and practice can help turn the tide in the catastrophic global AIDS pandemic that has been declared a threat to our own national security.

Thanks to the very hard work of many people inside and outside of government, we have a growing arsenal of powerful weapons to use in the fight against HIV and AIDS. Youth culture and the virus itself are always changing, and our prevention and treatment approaches must keep pace. We must take full advantage of the sound strategies that we have at our disposal -- our children and our future are at stake.



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Attachment A

ACKNOWLEDGEMENTS:

In considering a course of action, ONAP sought advice from adult AIDS experts inside and outside of government, and from young people themselves. An advisory group was invited to provide guidance; we appreciate their contributions and have listed their names and affiliations at the time of initial group meetings below.

In addition, early in the process of writing this report, a focus group was conducted with HIV-positive young people to insure inclusion of their critically important point of view. For reasons of confidentiality, the young people who participated in the focus group are not listed here, but we are deeply grateful for their time and frankness.

Finally, we would like to acknowledge the helpful comments on a draft of this report that were provided by all the Federal agencies and offices the report mentions and from a number of others. ONAP particularly appreciates the support provided for development of the report from HRSA and the AIDS Alliance for Children, Youth & Families.

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Attachment B

Recommendations from
Youth & HIV/AIDS: An American Agenda
March, 1996

Action Requiring Cooperation From All Levels of Society

- ▶ Young people, parents, schools, and communities must be integral partners in developing, delivering, and evaluating HIV prevention approaches for adolescents.
- ▶ Innovative, creative prevention efforts aimed at young people must be encouraged, adequately funded, and evaluated, and—when found to be effective—broadly disseminated.
- ▶ Comprehensive HIV/AIDS education—as part of comprehensive health education—should be available to all young people in all fifty states and U.S. territories.
- ▶ Routine counseling and voluntary HIV testing should be made more accessible, developmentally appropriate, and affordable to young people.
- ▶ HIV-positive adolescents should be linked to a continuum of health care and support services that will extend their life span and provide them with the information and skills they need to reduce the likelihood of further transmission.
- ▶ Adolescent-specific biomedical and behavioral research should be increased to enhance our knowledge of the progression of HIV disease in adolescents and of the effectiveness of HIV prevention approaches and of HIV/AIDS treatments.

The Federal Role

- ▶ DHHS should create a forum of young people who are infected or affected by HIV as well as their parents, advocates, and providers to work with Federal officials to help identify and articulate the needs of adolescents in fashioning Federal responses to HIV and AIDS.
- ▶ HRSA should encourage the inclusion of young people and their advocates on AIDS care planning councils to help identify local needs and ways to target Federal funds to help meet the distinct developmental and comprehensive care needs of youth.
- ▶ CDC should encourage the inclusion of young people and their advocates in AIDS prevention planning councils to provide their unique perspective of the needs of youth in prevention efforts.
- ▶ The Federal government should continue to help the nation's schools and other youth serving agencies implement comprehensive programs to prevent the spread of HIV among young people.

- ▶ NIH and the Food and Drug Administration should continue to encourage the enrollment of adolescents in government and industry sponsored HIV/AIDS clinical trials.
- ▶ The Public Health Service should work with the researchers, clinicians, medical community, and patients to develop appropriate clinical practice guidelines for adolescents with HIV/AIDS.
- ▶ In releasing data from clinical trials, NIH and FDA should include specific data related to adolescents. In those cases where the number of adolescents participating in a trial is too small, anecdotal data should be released on a limited basis to allow clinicians an opportunity to begin building a base of information for their use in treatment.
- ▶ The Federal government should support expanded access to testing and counseling for young people. The CDC guidelines for testing and counseling should address the special needs of adolescents, such as developmental issues, processes for consent, confidentiality, and payment for services. As part of a grant application for counseling and testing funding, states should demonstrate the availability of testing and counseling services for young people.
- ▶ SAMHSA, CDC, and HRSA should collaborate on substance abuse treatment and prevention strategies affecting adolescents to ensure a coordinated effort.

Attachment C

GLOSSARY

ACTG	Adult AIDS Clinical Trial Group, sponsored by NIH.
AIDS	Acquired Immunodeficiency Syndrome
AMHARN	Adolescent Medicine HIV/AIDS Research Network, sponsored by NIH
ASPE	Assistant Secretary for Planning and Evaluation, DHHS.
CDC	Centers for Disease Control and Prevention
CPCRA	Community Programs for Clinical Research on AIDS, sponsored by NIH
CPG	HIV/AIDS Prevention Community Planning Group
Determinants	Factors that have been shown to predict a certain outcome, for example, a disease or risk behavior
DHHS	Department of Health and Human Services
EPDSDT	Early and Periodic Developmental Screening, Diagnosis, and Treatment
FDA	Food and Drug Administration
HIV	Human Immunodeficiency Virus - the virus that causes AIDS
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HUD	Housing and Urban Development
IDU	Injection drug user
IRB	Institutional review board

Job Corps	Federal job training program for economically disadvantaged youth
Microbicide	A topical agent that kills virus, but not necessarily sperm
NIH	National Institutes of Health
OMH	Office of Minority Health, DHHS
ONAP	White House Office on National AIDS Policy
PACTG	Pediatric and Adolescent Clinical Trials Group, sponsored by NIH
Regimen	A recommended schedule and dosage of a drug or therapeutic agent or activity
RWCA	Ryan White CARE (Comprehensive AIDS Resources Emergency) Act
SAMHSA	Substance Abuse and Mental Health Services Administration
SCHIP	State Children's Health Insurance Program
SPNS	Special Projects of National Significance
STD	Sexually transmitted disease
Surveillance	The regular monitoring of cases of a specific disease or health event
YRBS	Youth Risk Behavior Surveillance

