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Subgroup/Office of Origin: National AIDS Policy Office

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OA/ID Number: 21075

FolderID:

Folder Title:

Youth Report [Folder 2] [2]

Stack:

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Row:

67

Section:

1

Shelf:

3

Position:

3

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable John A. Boehner
United States House of Representatives:

Dear Congressman Boehner:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

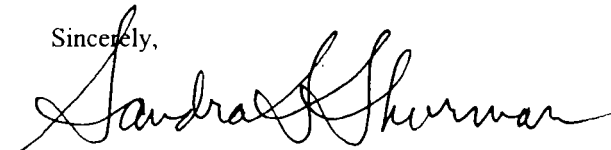
- Half of all new HIV infections in the United States are estimated to occur among those ages 13-24. That's 2 young people per hour whose lives will change forever.
- Binge drinking (recently reported by 48% of 21-year olds) and crack cocaine use (which has doubled since 1991 among those 12-17) are listed among other risk factors for HIV infection. Young people also lack access to STD treatment and drug treatment, programs with key roles in HIV prevention.
- New medical treatments have decreased AIDS-related death rates among young people, but most of those who have already been infected with HIV do not know that they have been infected. They cannot receive potentially life-saving medical treatment.
- Science has identified prevention approaches for in-school and out-of-school youth that are effective, but these evidence-based programs are not in widespread use throughout the country.

The report describes the Federal response to the problem to date, looking across the board at prevention, care and research activities. Finally, it makes a series of recommendations for future action. The recommendations include:

- Making sure that prevention programs for young people receive a share of HIV prevention resources that reflects their share of new cases of HIV infection.
- Investing in youth-friendly HIV counseling and testing and medical care across the country.
- Conducting research on questions like how HIV medications affect young people.
- Putting into place an ongoing national planning process that spans the HIV prevention, care, and research issues that affect young Americans.

I have enclosed a copy of the report, and it is available electronically (go to www.whitehouse.gov/ONAP and then click on ONAP Hot News). Additional printed copies are available from the National Prevention Information Network (1-800-458-5231). Thank you for your ongoing support of our domestic and global battle against HIV/AIDS. I hope that you will find this report useful in your policy efforts on behalf of American youth. They are counting on us.

Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

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WASHINGTON

October 23, 2000

The Honorable Lindsay Graham
United States House of Representatives:

Dear Congresswoman Graham:

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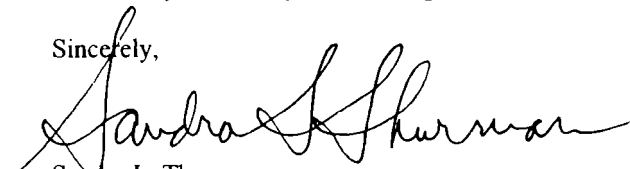
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October 23, 2000

The Honorable Marge Roukema
United States House of Representatives:

Dear Congresswoman Roukema:

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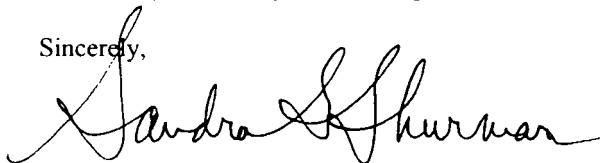
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The Honorable Thomas A. Petri
United States House of Representatives:

Dear Congressman Petri:

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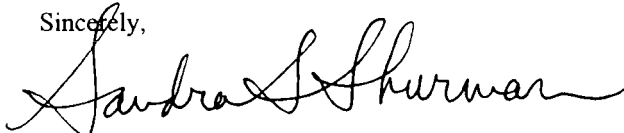
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The Honorable Van Hilleary
United States House of Representatives:

Dear Congressman Hilleary:

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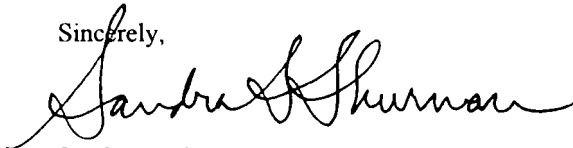
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The Honorable Fred Upton
United States House of Representatives:

Dear Congressman Upton:

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The Honorable David McIntosh
United States House of Representatives:

Dear Congressman McIntosh:

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The Honorable Jim Greenwood
United States House of Representatives:

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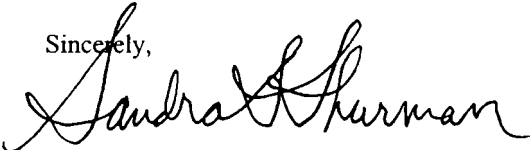
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The Honorable William F. Goodling
United States House of Representatives:

Dear Congressman Goodling:

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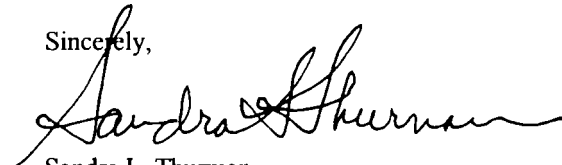
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The Honorable Ron Paul
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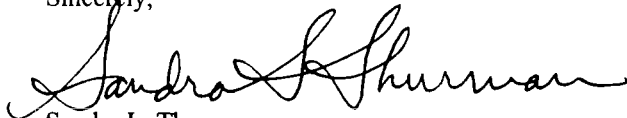
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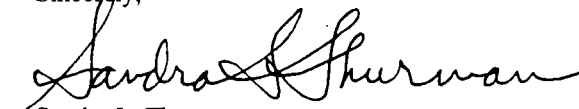
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The Honorable Sam Johnson
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The Honorable Michael N. Castle
Chair, Education and Workforce Subcommittee on Early Childhood, Youth, and Families
United States House of Representatives:

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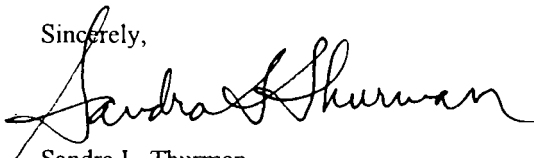
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October 23, 2000

The Honorable Jesse Jackson, Jr.
United States House of Representatives:

Dear Congressman Jackson:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

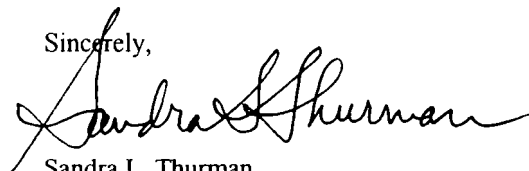
- Half of all new HIV infections in the United States are estimated to occur among those ages 13-24. That's 2 young people per hour whose lives will change forever.
- Binge drinking (recently reported by 48% of 21-year olds) and crack cocaine use (which has doubled since 1991 among those 12-17) are listed among other risk factors for HIV infection. Young people also lack access to STD treatment and drug treatment, programs with key roles in HIV prevention.
- New medical treatments have decreased AIDS-related death rates among young people, but most of those who have already been infected with HIV do not know that they have been infected. They cannot receive potentially life-saving medical treatment.
- Science has identified prevention approaches for in-school and out-of-school youth that are effective, but these evidence-based programs are not in widespread use throughout the country.

The report describes the Federal response to the problem to date, looking across the board at prevention, care and research activities. Finally, it makes a series of recommendations for future action. The recommendations include:

- Making sure that prevention programs for young people receive a share of HIV prevention resources that reflects their share of new cases of HIV infection.
- Investing in youth-friendly HIV counseling and testing and medical care across the country.
- Conducting research on questions like how HIV medications affect young people.
- Putting into place an ongoing national planning process that spans the HIV prevention, care, and research issues that affect young Americans.

I have enclosed a copy of the report, and it is available electronically (go to www.whitehouse.gov/ONAP and then click on ONAP Hot News). Additional printed copies are available from the National Prevention Information Network (1-800-458-5231). Thank you for your ongoing support of our domestic and global battle against HIV/AIDS. I hope that you will find this report useful in your policy efforts on behalf of American youth. They are counting on us.

Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Rosa DeLauro
United States House of Representatives:

Dear Congresswoman DeLauro:

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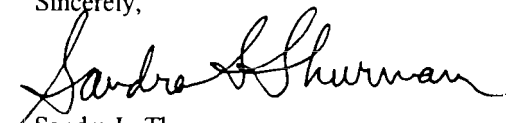
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Thad Cochran
United States Senate

Dear Senator Cochran:

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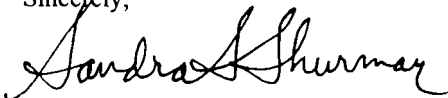
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Christopher J. Dodd
United States Senate

Dear Senator Dodd:

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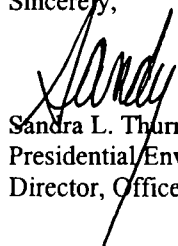
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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Barbara A. Mikulski
United States Senate

Dear Senator Mikulski:

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Sincerely,



Sandra L. Thyrman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Edward M. Kennedy
United States Senate

Dear Senator Kennedy:

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Sincerely,

Sandy

Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

you are the best! we love you bunches!

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Chuck Hagel
United States Senate

Dear Senator Hagel:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,



Sandra L. Thurman
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THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Sam Brownback
United States Senate

Dear Senator Brownback:

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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Susan M. Collins
United States Senate

Dear Senator Collins:

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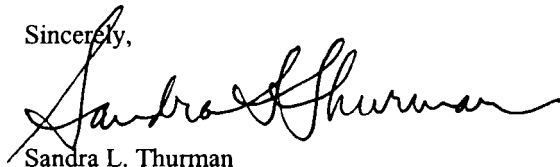
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THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Tim Hutchinson
United States Senate

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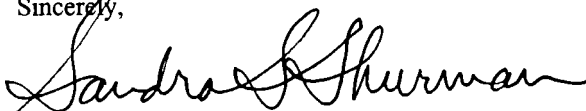
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
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THE WHITE HOUSE

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October 23, 2000

The Honorable Michael B. Enzi
United States Senate

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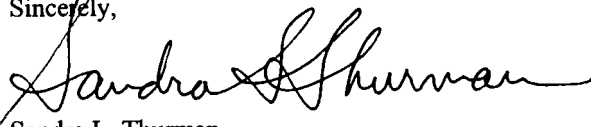
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
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The Honorable Mike DeWine
United States Senate

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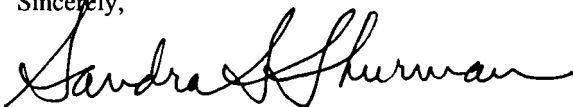
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
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THE WHITE HOUSE

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The Honorable Judd Gregg
United States Senate

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The Honorable James M. Jeffords
Chair, Committee on Health, Education, Labor, and Pensions
United States Senate

Dear Senator Jeffords:

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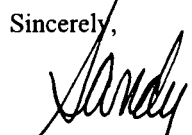
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- Investing in youth-friendly HIV counseling and testing and medical care across the country.
- Conducting research on questions like how HIV medications affect young people.
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I have enclosed a copy of the report, and it is available electronically (go to www.whitehouse.gov/ONAP and then click on ONAP Hot News). Additional printed copies are available from the National Prevention Information Network (1-800-458-5231). Thank you for your ongoing support of our domestic and global battle against HIV/AIDS. I hope that you will find this report useful in your policy efforts on behalf of American youth. They are counting on us.

Sincerely,


Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

Thanks so much for your leadership!

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Dianne Feinstein
United States Senate

Dear Senator Feinstein:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

- Half of all new HIV infections in the United States are estimated to occur among those ages 13-24. That's 2 young people per hour whose lives will change forever.
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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Patty Murray
United States Senate

Dear Senator Murray:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Herb Kohl
United States Senate

Dear Senator Kohl:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Harry Reid
United States Senate

Dear Senator Reid:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Daniel K. Inouye
United States Senate

Dear Senator Inouye:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

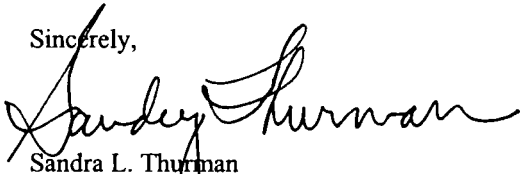
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Sincerely,



Sandra L. Thuman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Ernest F. Hollings
United States Senate

Dear Senator Hollings:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Tom Harkin
United States Senate

Dear Senator Harkin:

Tom

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sincerely,

Sandra

Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
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THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Jon Kyl
United States Senate

Dear Senator Kyl:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Ted Stevens
United States Senate

Dear Senator Stevens:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

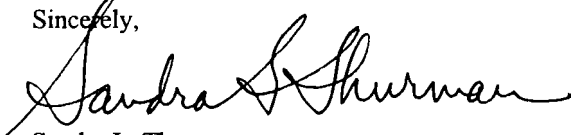
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Sandra L. Thurman
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THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Kay Bailey Hutchison
United States Senate

Dear Senator Hutchison:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Larry E. Craig
United States Senate

Dear Senator Craig:

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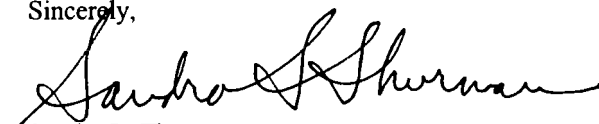
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Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Judd Gregg
United States Senate

Dear Senator Gregg:

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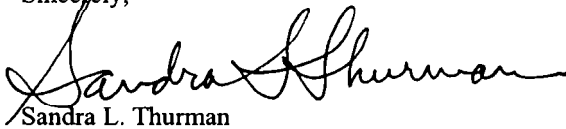
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Slade Gorton
United States Senate

Dear Senator Gorton:

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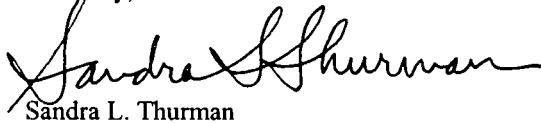
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Arlen Specter
Chair, Appropriations Subcommittee on Labor, Health and Human Services, and Education
United States Senate

Dear Senator Specter:

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I have enclosed a copy of the report, and it is available electronically (go to www.whitehouse.gov/ONAP and then click on ONAP Hot News). Additional printed copies are available from the National Prevention Information Network (1-800-458-5231). Thank you for your ongoing support of our domestic and global battle against HIV/AIDS. I hope that you will find this report useful in your policy efforts on behalf of American youth. They are counting on us.

Sincerely,



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE
WASHINGTON

October 23, 2000

The Honorable Harry Reid
Assistant Senate Minority Leader
United States Senate

Dear Senator Reid:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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THE WHITE HOUSE
WASHINGTON

October 23, 2000

The Honorable Bill Frist
United States Senate

Dear Senator Frist:

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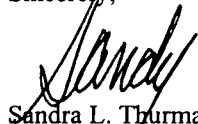
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Tom Daschle
Senate Minority Leader
United States Senate

Dear Senator Daschle:

I am writing at what I know is a very busy time to bring to your attention the newly released report from the White House Office of National AIDS Policy entitled, "Youth and HIV/AIDS 2000: A New American Agenda." The new report points out that:

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Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

THE WHITE HOUSE

WASHINGTON

October 23, 2000

The Honorable Don Nickles
Assistant Senate Majority Leader
United States Senate

Dear Senator Nickles:

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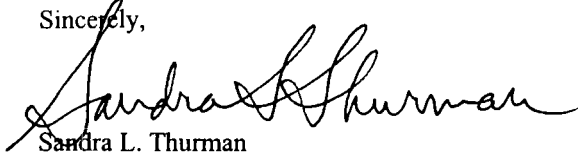
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Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
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THE WHITE HOUSE
WASHINGTON

October 23, 2000

The Honorable Trent Lott
Senate Majority Leader
United States Senate

Dear Senator Lott:

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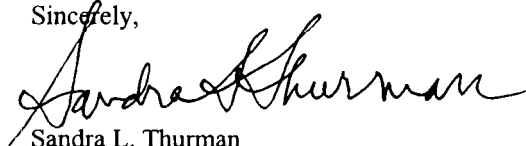
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YOUTH AND HIV/AIDS REPORT WORKING GROUP MEETING
White House Office of National AIDS Policy
Friday, July 16, 1999 ♦ 9am - 4pm

MEETING AGENDA

- 8:30-9:00 Continental breakfast
- 9:00-9:30 Welcoming remarks
- Sandra Thurman, White House Office of National AIDS Policy
 - David Harvey, AIDS Policy Center for Children, Youth & Families
 - Joan Holloway, Health Resources and Services Administration
 - Daniel Montoya, Presidential Advisory Council on HIV/AIDS
- 9:30-9:45 Introductions
- 9:45-10:15 Background on 1996 Youth Report/Summary of recommendations
Facilitated by Todd Summers
Remarks by Miguel Bustos, David Harvey, Jane Sanville
- Purpose
 - Process
 - Follow-up/Implementation
 - Usefulness and significance
- 10:15-10:30 Break
- 10:30-11:45 Discussion: assessment of response to 1996 Youth Report
Facilitated by Clark Moore
- Review and assess implementation of key recommendations:
 - Prevention
 - Counseling and Testing
 - Care and Services
 - Research
- 11:45-12:30 Discussion: developing Youth Report 2000
Facilitated by Todd Summers
- Purpose/role of working group
 - Vision for Youth Report 2000
 - Process
 - Roll-out strategy
 - Timeline

- 12:30-1:30 Lunch
- 1:30-1:45 Report-out from Voices '99 Youth Forum
Presenters: Margaret Campbell and Clark Moore
- 1:45-2:00 Charge to break-out groups
- 2:00-2:45 Small groups meet to generate priority recommendations for Youth Report 2000
- Group A (facilitated by Clark Moore):
- Prevention
 - Counseling and Testing/Casefinding
- Group B (facilitated by David Harvey):
- Care and services for HIV-positive youth
 - Research
- 2:45-3:00 Break
- 3:00-3:30 Small groups meet to refine and prioritize recommendations
- 3:30-3:45 Small group report-outs/discussion
- 3:45-4:00 Wrap-up/concluding remarks/next steps
- 4:00 Adjourn



Recommendations to the Presidential Advisory Council on HIV/AIDS **June 1998**

The following recommendations expand on key issues and recommendations contained in the 1996 White House Report, *Youth & HIV/AIDS: An American Agenda*. The recommendations also summarize some of the top policy issues which have consistently been identified by young people, service providers, and advocacy organizations.

Prevention

- The Administration should direct CDC to ensure that HIV prevention activities, including CDC-funded activities at the local level, more equitably address the needs of youth at highest risk for HIV infection, including youth of color, young women, and young men who have sex with men.
- The President must provide strong and vocal support for federal funding for comprehensive HIV/STD prevention and family planning programs that include information about disease and pregnancy prevention methods other than abstinence.

Counseling and Testing

- The Administration should direct the CDC to ensure that all CDC-funded HIV counseling and testing programs are accessible and appropriate for young people. Funding and support for youth-specific casefinding and counseling/testing programs should be expanded.
- The Administration should direct HHS to expand training and assistance programs for health care providers on improving the quality and availability of HIV counseling and testing for youth.

Care and Treatment

- The President should seek expanded funding and support under the Ryan White CARE Act and other Federal programs for comprehensive, community-based health care services that address the medical and psychosocial needs of HIV infected youth.
- The Administration should work to expand eligibility under the Children's Health Insurance Program (CHIP) and Medicaid to ensure that all youth in all states and territories have comprehensive health coverage.

- The Administration should direct HRSA to expand and strengthen training and technical assistance for HIV service providers and youth service providers to help them respond to the unique needs of young people living with and at risk for HIV.

Research

- The President should direct HHS to convene a working group consisting of representatives from Federal agencies, researchers, youth service providers, advocates and young people to develop a coordinated Federal agenda for HIV/AIDS research on adolescents and young adults. This agenda, which should be updated regularly, would help to coordinate existing efforts and to identify key research gaps. It should address the full range of research related to HIV/AIDS epidemiology, prevention, care and treatment.
- The Administration should direct NIH to provide incentives, training and technical assistance to units of the Adult AIDS Clinical Trials Group (AACTG), the Pediatric AIDS Clinical Trials Group (PACTG) and Clinical Programs for Clinical Research on AIDS (CPCRA) to promote access to clinical research opportunities for HIV infected adolescents and young adults.

DRAFT
AIDS Policy Center for Children, Youth & Families
Youth Forum: Bridging HIV Prevention, Testing and Care for Youth
Saturday, May 22, 1999

ABSTRACT

On May 22, 1999, AIDS Policy Center for Children, Youth & Families convened a day-long meeting of adolescents in Washington, D.C. to gather their recommendations on improving young people's access to HIV/AIDS testing, treatment and care programs. These recommendations will provide input to the Centers for Disease Control and other key federal agencies. The recommendations will also inform the process to update the Office of National AIDS Policy report *Youth & HIV/AIDS: An American Agenda*.¹

The young people's broad recommendations follow and are listed in more detail in the body of the report. It is important to note that many of the recommendations made by the participants are in place, at least in some communities. A broader issue may be the dissemination of protocols and best practices which help youth seek testing, counseling and care.

- Develop standards and protocols for treating young people. Create recommendations for provider training, supervision and support to improve health care delivery that recognizes young people's medical and developmental issues. Offer training opportunities to teach providers how to work with adolescents in general, and HIV-positive youth in particular.
- AIDS care providers as well as other health care providers must learn to treat the whole person. Adolescents are in need of a medical home and, for HIV-positive youth, this is often their AIDS treatment provider. Because a youth has HIV, however, does not mean they do not have other medical conditions or concerns with which they need help. In particular, young people's psychosocial needs are not being met; mental health services should be incorporated into other prevention and medical programs.
- Address the broad community problems in which the AIDS epidemic is rooted. Communities must offer young people real economic opportunities, the chance for academic attainment and alternatives to high-risk behaviors. The youth described HIV/AIDS as connected to every social issue; that communities must pay attention to, and invest in, their youth. This is particularly vital during early adolescence in communities where HIV/AIDS is already concentrated.
- Address economic barriers which prevent people from accessing preventive health care and AIDS treatment services. In particular, work to overcome lack of insurance and prescription coverage.

- Improve HIV/AIDS prevention education offered by schools and communities, as well as that available to young people outside the school setting. Teens want more graphic and reality-based information, provided earlier, about a broader range of topics. To reach young people who are not in school, HIV/AIDS education, testing and care programs must make more of an effort to bring messages where the young people are: in community settings and through the media. To be effective, prevention education must also build skills and address power dynamics that affect teen (particularly female) decision making.
- Implement targeted testing campaigns that focus on populations at highest risk for infection. In particular, provide messages about safe sex and HIV tests to young men who have sex with men but who do not identify as gay or bisexual. Use young people in these campaigns, so that teens see faces that look like themselves. Information about what the test is like and where it is available should be widely distributed in locations where young people hang out.
- Make health care facilities adolescent-friendly and offer information about these sites to all hotline callers. Adolescent friendly sites: have anonymous testing, use oral swabs, treat their teen clients with respect, offer a range of counselors so youth can select someone with whom they feel comfortable, provide on-going counseling while youth are waiting for their results and afterwards, and provide accurate (and attractive) materials.
- Link testing with care, preferably comprehensive care. Facilitate young people's passage from the testing facility to care by linking the two services; providing tests within a medical setting helps make this transition. Staff at testing sites who remain involved with the young person until they are established in care can make an enormous difference.
- Develop protocols for confidentiality. This group was unanimous in their experience that providers routinely violate young people's confidentiality and that this is a major barrier to seeking testing and continuing in care. Providers should also help teen clients understand their rights as patients, and should respect these rights.
- Offer on-going and meaningful support to youth as well as to their parents and caregivers. When a youth receives an HIV-positive diagnosis, work with him or her to understand and deal with their situation and future decisions. HIV-positive youth also need help building connections and support networks with other HIV-positive teens.

YOUTH AND HIV/AIDS REPORT WORKING GROUP

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Youth and HIV/AIDS 2000: A New American Agenda

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Youth and HIV/AIDS 2000: A New American Agenda

SUMMARY

1. AIDS is not over. There are 40,000 new HIV infections every year, and half of those infected are young people. This estimate has remained constant for several years.
2. The best treatments fall far short of a cure and we have no vaccine. Behavior change is the only way to prevent AIDS and protect America's youth.
3. All young people need the tools to protect themselves from AIDS. Studies have shown that certain prevention programs can reduce risk behavior, but these programs are not offered in most schools.
4. We still need answers to key questions about preventing and treating HIV and AIDS in young people. For example, we need to know how medical treatments for HIV affect a person who is still developing physically.
4. AIDS hits hardest among youth already fighting poverty, racism, sexism and homophobia. Many lack access to health care, are out of school, and are exploited by adults. They urgently need community-based prevention programs that provide HIV information, teach skills, and address the other daunting challenges they face.
5. Most young people who are already HIV-infected don't know it. If they are to have any hope of long and productive lives, they must be encouraged to get tested and then must have access to the health care and support they need. Age-appropriate services are in short supply.
6. Leadership and resources from the Federal government have done much to protect and support young people, but much more remains to be done. Not only more resources, but also smarter use of existing resources are key to stopping AIDS with this generation of American youth.

BACKGROUND

- quote from young person -

Alarmed at the threat HIV posed to America's young people, the Office of National AIDS Policy issued a wake-up call to the nation in a 1996 report, *Youth and HIV/AIDS: An American Agenda*. With young Americans becoming infected with HIV at the rate of one per hour, the report named American youth a "generation at risk." Today, we report again on the status of the epidemic among young people, acknowledging progress made and calling for a reinvigorated national response to the problem.

Major advances have been made in the past four years. Since 1996, protease inhibitors and other new medical treatments have dramatically reduced the AIDS death rate for young people. This good news is a return on our national investment in AIDS research, but the good news is only part of the story. It is deeply distressing that we have not seen a decline in new HIV infections among youth in this country. We must refine our strategy and increase our commitment to prevent this brutal disease that has been recognized as an issue of national security.

In considering a renewed course of action, the Office of National AIDS Policy (ONAP) sought advice and counsel from AIDS researchers and care providers, Federal officials leading the government response to AIDS, and young people themselves. Over the past year, an informal working group assessed progress since the last report and made recommendations for the future. Joining ONAP as partners in coordinating this effort were the Presidential Advisory Council on HIV and AIDS, the Health Resources and Services Administration (HRSA), AIDS Alliance for Children, Youth & Families, and representatives of a number of youth-serving agencies.

Recognizing the importance of youth speaking for themselves, we started by consulting with a racially and ethnically diverse group of young people who came together from across the country to share their experiences and insight. These outspoken young men and women ranged in age from 12 to 25. The group included at-risk, HIV-positive, straight and gay individuals. They were generous with their time and bold in their vision; we are deeply grateful to them for their frankness. Since then, young people and other advisors have continued to provide invaluable input for this report: *Youth and HIV/AIDS 2000: A New American Agenda*. With its release, we urge the Federal Government, local communities, parents and others to join together in the vigorous, immediate action necessary to protect and care for young people. The lessons we learn along the way will benefit our young people and the entire global community.

FINDINGS

The Problem:

The AIDS epidemic is not over, and young people are not immune. Half of all new HIV infections are thought to occur in young people under 25.

- Over 120,000 young adults in the United States have developed AIDS in their twenties. The delay between HIV infection and the onset of AIDS means that most of these young people were infected with HIV as teenagers.
- Our best estimate is that one young American under the age of 20 is still contracting HIV every hour of every day, on average.

The total number of youth in the U.S. who have been infected with HIV is unknown, but public health officials believe that it is substantially greater than the number who have AIDS.

Millions of American youth are still engaging in sexual behaviors that put them at risk for HIV/AIDS.

The HIV virus was contracted sexually in the majority of cases of HIV infection among young people.

- Most American youth are sexually active by the time they reach age 19.
- Each year, three million adolescents contract sexually transmitted diseases (STDs). That is, in a year's time, about one in four sexually experienced teenagers contracts an STD. Of the 12 million Americans with STDs, about two-thirds are young people under age 25. Obviously, many adolescents are engaged in unprotected sex – behavior that places them at risk of HIV infection.
- A recent seven-city survey of 3,000 young men who have sex with men found that, in the last six months, 30% had engaged in unprotected anal sex, an especially high-risk activity.

Fortunately, there has been a drop in sexual risk behaviors and an increase in condom

use among sexually active youth.

(graph)

The percentage of high school students who have had sexual intercourse decreased from 54% in 1991 to 48% in 1997, while the percentage of sexually active high school students using condoms increased from 46% to 57% during the same period. Although these numbers are improvements, the number of sexually active young people not using condoms remains perilously high.

Substance abuse also contributes to HIV risk in young people. It can impair judgment in sexual situations and involve needle sharing, a direct means of HIV exposure.

- There is a normal tendency for young people to take risks. Those who engage in one risky behavior often engage in others. Young people who drink or take drugs are much more likely to have sex.
- In a recent survey of high school students in the United States, 25% of those who had ever had sex said they were under the influence of alcohol or drugs the last time they had sex.
- In a national household survey, 30.8% of those 18-25 years of age reported binge drinking. They had had at least 5 drinks on the same occasion within the last month.
- More than one in 50 high school students admitted injecting illegal drugs.

Some young people are in even greater jeopardy.

Although all young people who engage in HIV risk behavior are at risk of infection, certain groups have been particularly hard hit. Young heterosexual women -- particularly young women of color -- and young gay and bisexual men *[are thought to account for three-quarters of HIV-infected youth??? Where does this stat come from? Of AIDS cases, it's about 65, and fewer of reported HIV cases]*.

- More females than males are now being diagnosed with HIV in the 13 to 19 year old age group. In this group, six out of 10 HIV infections reported last year were among females. In the next oldest group, 20 to 24 year olds, infections among

young women are on the rise; they represent one-third of all HIV infections ever reported, but 44% of last year's infections.

- In young women entering the Job Corps, rates of HIV infection were seven times higher among African Americans than among their white counterparts.
- Disadvantaged young people from the South and Northeast had the highest rates of HIV infection in the Job Corps data. These areas of the country appear to have prevalence rates of up to 1 per 100 young women, with the highest rates in the District of Columbia, Florida, Louisiana, Maryland, South Carolina, Virginia and Connecticut.
- Far more than half of the young men aged 13 to 24 who were diagnosed with HIV last year were exposed to the virus through sex with other men.
- Young urban men who have sex with men show alarming rates of HIV infection -- 7% overall -- with higher rates among African Americans and Latinos than whites.

African American and Latino youth continue to be disproportionately affected by HIV and AIDS.

(graph)

Each of these groups makes up about 15% of U.S. teenagers. African Americans account for 49% of the 3,564 AIDS cases reported among adolescents aged 13-19 through June 1999, and 66% of 4,470 reported HIV infections. That same year, Hispanics represented 20% of AIDS cases among teens.

There are 7 times as many cases of AIDS among those ages 20 to 24, and people from racial or ethnic minority groups account for over 60% of them. The racial/ethnic disparity is even greater among young women: in this age group, women of color account for 78% of AIDS cases.

(graph)

Youth who drop out of school, run away from home, are incarcerated, or are homeless are still among those at highest risk for HIV and AIDS.

- Some 3.6 million young people (11% of those 16-24 in the United States) are not enrolled in a high school program and have not completed high school. Compared

with youth in school, out-of-school youth are significantly more likely to have had sex, to have had more than 4 sex partners, and to have failed to use protection the last time they had sex.

- In 1998, there were more than 2.6 million arrests of youth under age 18. Over 100,000 juvenile offenders are in residential placement on a typical day. Compared with other youth, youth in detention have engaged in HIV risk behaviors at dramatically increased rates, but they know less about HIV.
- Estimates of the number of homeless and runaway youth range from 730,000 to 1.3 million. Many of these young people use injection and other drugs and exchange sex for money, food, or shelter. One study of homeless youth in four cities found a median HIV infection rate of 2.3%. Some shelters have reported rates as high as 16%.

Like adults in this country, America's young people may be growing complacent about AIDS.

Although most young people see AIDS as a major social problem and know the basics about how to protect themselves from HIV, they tend not to think that they are personally at risk.

- In one recent survey, 87% of young Americans do not believe that they are at risk for HIV infection.

This impression can be tragically mistaken, but it can undercut the motivation to avoid sex or use condoms. Exaggerated expectations of what medical treatments for HIV can do and lack of hope for a rewarding future can also contribute to a young person's complacency about HIV.

Prevention efforts fall far short of the mark.

Most states have policies that support HIV prevention in schools, but local communities make their own decisions about what goes on in classrooms. We have credible evidence that several prevention programs lower youth risk behavior, but many school districts have chosen not to adopt one of these model programs. To make matters worse, young people who don't attend school regularly are among those at highest risk of HIV infection., but there continues to be a dangerous dearth of good, community-based HIV prevention programming for young people.

- Eighty-six per cent of junior and senior high schools list HIV prevention as a topic in a required course, and 77% of teachers say that HIV was a major topic for their courses, but only 37% of the teachers discussed the correct use of condoms.
- In the two years prior to a national survey of teachers, only 31% received training on HIV-prevention.
- The shortest of the group-based prevention programs that work is 5 sessions long. Almost 50% of teachers who deal with HIV spend only 1 or 2 class periods on the topic.
- Young people between 13 and 24 constitute only 16% of the population at large, so they are heavily over-represented in projected HIV and AIDS statistics. Nonetheless, only 25 of the 120 community planning groups charged with setting priorities for local use of Federal HIV prevention funds identified youth as a priority target audience.
- Only 33 states and the District of Columbia have organizations that provide support for gay youth, and most of these have services only in one or two major cities. The overall need for community-based, HIV prevention services for all at-risk, out-of-school, and institutionalized youth has not even been quantified.
- STD treatment reduces the risk of HIV infection, and an STD diagnosis constitutes a powerful “teachable moment” for HIV prevention. However, both screening and treatment services for STDs are underfunded. For example, in the country’s most populated areas, chlamydia screening reaches only 20% of the young women in need.
- Research on creative new prevention program models has lagged far behind medical research. For example, programs designed to help parents communicate effectively with youth about HIV prevention are only now being evaluated scientifically.

Most young people who are HIV-infected don't know it.

Millions of young people who have engaged in high-risk behaviors do not know their HIV status. There are an estimated 250,000 Americans who unaware that they are HIV-infected, and half of them are thought to be young people.

To take advantage of promising new treatments for HIV, young people must know that they are infected. They should be encouraged to seek voluntary testing, linked to

a comprehensive system of care, and receive appropriate health care and other supportive services.

Young people face many barriers to HIV counseling and testing.

Everyone who engages in behaviors that carry risk for HIV infection should talk to a health care provider or other HIV counselor and get tested for HIV. Those who discover that they are HIV-positive have the information they need to seek health care and to learn how to protect themselves and their partners. Those who test negative stand to benefit from services designed to help them stay HIV-negative.

But many youth at risk have no doctor or other health care provider to turn to for advice and don't know how or where to get an HIV test. Some counseling and testing facilities are open primarily during school hours. Many sites offer counseling in English only. In some states, a parent's consent is required before an adolescent can be tested for HIV, and some states allow or require parental notification of a positive test. For youth who feel extremely uncomfortable or unsafe discussing sex or drug-related issues with their parents, these policies present a major barrier to testing. Some young people are under the false impression that they are tested during routine medical exams (e.g., gynecological check-ups), and assume that they would be notified if they tested positive. Young people who manage to overcome initial barriers to HIV testing often fail to return for their test results.

HIV counseling and testing helps a young person most when it is tailored to his or her mental and emotional state, language, culture, and sexual orientation. There are too few youth-friendly testing sites with staff who are trained to work with young people in a supportive way that accommodates their unique needs.

HIV-infected youth are not receiving the health care they need to live as long and productively as possible.

Because most young Americans with HIV infection don't know they are infected, they can't receive proper medical care. In fact, many young people find out they are infected only after they become seriously ill, too late to benefit from early treatment.

Compared with children and older adults, young people are much less likely to have medical insurance. Even when they have insurance, they have difficulty finding health care providers who are experienced with youth and also know a lot about HIV. Young people who live in rural communities face particular difficulty in finding appropriate services close to home, and confidentiality concerns are often heightened in small communities.

- In 1997, 29.3% of low-income youth 14 -18 years old lacked insurance, one and one half times the percentage for low income children under 5 years of age (17.6%).
- Roughly one in three 18-24 year olds does not have health insurance, and the number of uninsured continues to climb each year.
- Two million 19-20 year olds had neither public nor private medical insurance in 1997. Low income people aged 19-20 had the highest uninsured rate of all -- 47.7%.
- The largest gaps in medical services for youth are in substance abuse and mental health services, both of which are central to the needs of many HIV-infected youth.

Medical research has led to great strides in HIV/AIDS treatment, but much remains to be learned about the progression and treatment of the disease in adolescents.

- Drug therapies have produced dramatic reductions in death rates from AIDS, with a 35% decline among those 15 to 24 years of age from 1996 to 1997 alone.
- Unfortunately, too few adolescents have been included in medical research to make it possible to find out whether they will react to AIDS medications and dosages the same way adults do.

Clinical research with HIV-infected youth is hampered by the small number of HIV-positive youth receiving care, and by the unique challenges of recruiting and retaining adolescent research participants. AIDS research programs for HIV-positive youth are much less developed than those for children and adults. Young people also continue to make up a very small percentage of participants in clinical studies that are not youth-specific. It is very important to include young participants in AIDS-relevant medical research; young people should be asked for guidance in recruiting their peers and keeping them involved.

The Response:

Since the 1996 report to the President, *Youth and HIV/AIDS: An American Agenda*, significant progress has been made on several fronts. Promising programs for HIV prevention and care for young people have been created or strengthened, and important research has been conducted. Almost across the board, however, these youth-specific activities have amounted to a good start, falling far short of addressing the full magnitude of the needs of young people in the United States. We must expand effective initiatives exponentially and, at the same time, search for new and better strategies. This work will require more resources and smarter use of existing resources, but there is no more worthwhile investment.

Prevention

The Federal government supports a wide range of programs to prevent HIV infection, most of which are administered by the Centers for Disease Control and Prevention (CDC). Other Federal agencies also play key roles. Between 1996, the year of the last White House report on youth and HIV/AIDS, and FY 2000, Federal funding for HIV prevention programs increased from \$638 million to \$1057 million. During that period, CDC funding for domestic HIV prevention increased from \$584 million to \$695 million.

The major source of federal funding for community-based HIV prevention programs is CDC's cooperative agreements with health departments. The agency supports all 50 states, seven territories, the District of Columbia, Puerto Rico, and six cities in conducting a variety of HIV prevention activities. They include HIV counseling and testing, health education and risk-reduction, public information, and community planning. Local program priorities are determined by community volunteers and health department staff who serve on community planning groups (CPGs). During FY 1999, \$258 million went to local areas through the cooperative agreements, and CPGs allocated about \$60 million to local organizations that provide community-based prevention programs to youth.

The first ONAP report recommended greater youth involvement in the CPGs. Steps to involve more young people have been taken, including funding the National Association of State and Territorial AIDS Directors to compile a case study of CPG experiences with youth involvement.

CDC has also awarded additional funding directly to some local organizations -- mainly those that provide prevention services to hard-hit racial and ethnic minorities -- in the last two years. Many of these grantees serve youth along with other age groups.

Finally, CDC receives and distributes funds for HIV prevention in schools. Each year since FY 1996, about \$45 million has been provided to state and local education agencies to improve the quality and effectiveness of school-based HIV prevention programs. The CDC recommends that HIV prevention be undertaken in the context of comprehensive school health programs, and trains more than 180,000 teachers each year in the administration of such programs.

The "Research to Classroom" project actively promotes curricula that have good evidence of reducing sexual risk behaviors. In the last four years, new curricula have met the stringent scientific criteria CDC uses to assess prevention programs, and a constantly updated list of evidence-based curricula has become available on a CDC webpage (<http://www.cdc.gov/nccdphp/dash>).

Consequently, most students are learning at least something about HIV in school. The percentage of high school students who said they were taught about HIV/AIDS in school increased from 86% in 1995 to 92% in 1997. Many schools have established notable HIV education programs, but not all students get the comprehensive HIV education they need to protect their health. Local political constraints, limited coordination between school officials and health departments, and level funding have stood in the way of making evidence-based HIV education widely available in schools. Wider availability of these high quality programs was a major recommendation in the last ONAP report.

Although none of the evidence-based curricula uses an "abstinence-only" approach, Congress dedicated the largest increase in Federal HIV prevention funds since the 1996 report to abstinence-only programming. The 1996 welfare legislation made a total of \$250 million per year available to support programs that have "...as [their] exclusive purpose, teaching the social, psychological, and health gains to be realized by abstaining from sexual activity." The legislative language has been interpreted to mean that this large pot of money cannot be used to support the more comprehensive prevention programs that have been shown to be effective, especially among sexually active youth. To date, research has shown that, to change risk behavior, programs must provide information about safer sex, condoms, and contraceptives in addition to encouraging abstinence. Some abstinence promotion programs may deserve further scientific study. However, it is cruelly ironic that schools in our inner-city areas where HIV risk is greatest are least financially able to decline funding for unproven abstinence-only instruction.

As important as school-based HIV prevention education is, it will never reach all young people who need it. Community-based programs are an essential part of the mix. They enable out-of-school youth to receive life-saving information through trusted channels, in convenient places, and in formats that have been tailored to their diverse needs.

Increasingly, community-based programs are responding to the reality that risk behavior does not occur in a vacuum. Young people have other pressing concerns (e.g., poverty, lack of adult attention, sexual identity issues and drug and alcohol dependency) that must be addressed if they are to sustain the motivation to avoid unsafe sex.

Drug and alcohol prevention and treatment are truly essential elements in the array of services necessary for HIV prevention for young people. Substance use increases risk and refusal skills learned in the context of drug prevention can help youth avoid sexual risks. The Substance Abuse and Mental Health Services Administration (SAMHSA) funds community-based programs that target youth, like its High Risk Youth Program. This nationwide system develops, documents, and disseminates successful approaches to preventing drug and alcohol use among youth in high-risk environments. In 1999, the Minority AIDS Initiative significantly increased SAMHSA's resources to support substance abuse prevention and treatment services for youth of color.

Despite these initiatives, the shortfall of youth-targeted, community-based services remains acute. As the last ONAP report emphasized, we need more widespread sharing of information about programs that work, more support for reproducing strong existing models, and more good new HIV prevention ideas.

Over the last few years, there has been some Federal support for new types of HIV prevention. The major new approaches include interventions to enhance parent-teen communication, youth development and service learning programs, "safer schools" interventions, multi-level interventions (e.g., programs that target students, their parents, and their teachers), and social marketing campaigns.

The National Institute of Drug Abuse (NIDA) and CDC have placed special emphasis on social marketing -- the use of media campaigns and other marketing strategies to influence behaviors and attitudes -- because it can reach so many young people. NIDA distributed post cards containing science-based information on drug abuse and addiction in locations such as record stores, coffee shops, bars, cinemas and gyms.

In the last two years, CDC released radio and TV spots tailored for minority youth audiences in the last two years. Also, CDC's HIV Prevention Marketing Initiative (PMI) supported five communities in planning and launching youth-oriented social marketing campaigns. At each site, hundreds of teens participated in intensive workshops, and thousands were exposed to prevention messages through print, radio, and television ads. Community volunteers learned to think like marketers, and youth exposed to the PMI messages reported reduced risk behavior. From 1995 to 1998, CDC also funded 20 national organizations to establish and evaluate HIV/AIDS prevention communications

programs. Six of these organizations specifically targeted young people. For example, the National Council of Negro Women is conducting a national HIV prevention health communications project focusing on young African American women.

In its newest social marketing work, CDC is developing a campaign to encourage high-risk individuals to get HIV testing and counseling. Young people with HIV-infection, most of whom are unaware that they are infected, are a key target audience for this campaign. Getting HIV testing and counseling is the first step on the road to adequate care.

Since 1996, Federal agencies have taken some important steps to expand HIV counseling and testing for youth:

- CDC, which provides most federal funding for HIV counseling and testing, is developing guidelines to help HIV test counselors respond to the unique needs of adolescents and young adults.
- An emphasis on young people is now part of National HIV Testing Day, a CDC-sponsored campaign designed to encourage everyone to know his or her HIV status.
- With funding from HRSA and private sources, the National Institutes of Health's Adolescent Medicine HIV/AIDS Research Network created Project ACCESS, a youth-oriented social marketing campaign to promote HIV counseling and testing. Using print, radio, and television ads, the project reaches young people through language and images that reflect youth culture. The project was pilot tested in New York in 1997 and 1998. Project ACCESS is now expanding to Baltimore, the District of Columbia, Los Angeles, Miami, and Philadelphia, with \$1.2 million from the Minority AIDS Initiative.

These and other Federal initiatives respond to calls in the first ONAP report for increasing the numbers of at-risk youth who are being tested and brought into care. However, the amount of Federal resources devoted to this effort is meager compared to the number of youth at risk of HIV infection. Much more remains to be done to provide developmentally appropriate, culturally competent HIV counseling and testing to all the young people who need it.

Monitoring the HIV Epidemic

In partnership with state and local health and education departments, CDC monitors various aspects of the epidemic by age group. A number of surveillance tools track HIV-related school policy, risk behavior, HIV tests given at publicly funded sites, reported cases of HIV and AIDS, and AIDS-related deaths. These statistics are stripped of any information that could identify individuals, reported to CDC, assembled and made available to the public on the worldwide web and in libraries across the country.

To facilitate our national HIV prevention efforts, CDC provides technical assistance to local programs directly and via national organizations, some of which focus on youth. One outcome of this assistance is a fledgling turn of community-based prevention programming dollars towards youth at risk.

Getting the Word Out About Youth and HIV

The National AIDS Hotline is a free source of information and referrals. Between July 1999 and June 2000, the Hotline, which is funded by the CDC, received approximately 143,580 calls from people ages 18 to 24 and 39,484 calls from people under age 18. In addition, the Hotline's Classroom Calls program reached more than 4,000 young people in classrooms across the country. There were also thousands of calls to the STD hotline. These phone services will merge in August, 2000.

The National Prevention Information Network (NPIN), also funded by the CDC, provides information about HIV/AIDS, STDs, and tuberculosis to people and organizations working in prevention, health care, research, and support services. Through a toll-free hotline and a web site, NPIN provides information, publications, and referrals on youth issues to thousands of researchers, educators, health care professionals, parents, and young people each year.

Care and Treatment

The Federal government plays an essential role in providing health care coverage for young people and sponsors HIV/AIDS-specific treatment programs for which youth are eligible. Although identifying the young people in need of treatment for HIV and AIDS and linking them to adequate systems of care have not been easy, some progress has been made in the last four years in coverage and availability of services.

Since the 1996 report, significant progress has been made in extending health insurance to more adolescents.

- Since it began in 1997, the State Children's Health Insurance Program (CHIP) has helped insure over 1 million children and adolescents under the age of 19 whose family incomes are too high to qualify for Medicaid but too low to afford private health insurance. States expect to enroll 2.6 million children and youth in the program by September 2000. However, enrolling eligible children and youth in CHIP has been a major challenge. In addition, an estimated 41% of uninsured children and adolescents live in families with incomes that are too high to qualify for most state CHIP programs.

Although CHIP programs have helped many teens -- and probably reduced medical costs by treating problems before they become serious -- health insurance for older adolescents and young adults is still sorely lacking. CHIP and other public health insurance programs typically limit coverage to youth under age 19. This has contributed to the major gap in coverage for young adults.

The Federal government supports a wide array of AIDS-specific programs that create a safety net of care and support for Americans living with HIV and AIDS. Since the 1996 report, discretionary Federal spending on these programs increased from approximately \$1.3 billion to \$2.2 billion in FY 1999. Despite this considerable investment in care, the number of HIV-positive youth participating in such programs continues to be very small. In part, this is because many HIV-positive youth do not know they are infected. A lack of health insurance and health care providers with both HIV and youth expertise also play a significant part in keeping youth out of care, as do confidentiality concerns.

The Ryan White CARE Act is the largest discretionary federal program dedicated to HIV care and treatment. It has enabled communities across the country to provide care and support for people who are living with HIV/AIDS. The CARE Act, which is administered by HRSA, supports a wide range of community-based services, including primary and

home health care, access to medications, case management, substance abuse treatment, mental health services, dental care, nutritional services, and housing. As the number of people requiring care increased, the CARE Act has grown from a \$220.5 million program in 1991 to a \$1.5 billion program today.

The Ryan White Title IV program, which provides comprehensive HIV care and services for children, youth, women, and families, is leading the national effort to engage HIV-positive young people in care and keep them there. From 1995 to 1997 alone, the number of young people ages 13-24 served by Title IV increased by 225%. Title IV projects have been particularly successful at reaching young women, one of the fastest-growing HIV risk groups in the country.

In 1998, HRSA established a \$2 million Adolescent Initiative within Title IV to increase the number of HIV-positive youth, ages 13 to 24, receiving primary medical care and support in a youth-sensitive environment. This initiative, which represents a very small fraction of Federal AIDS care dollars, is now the only ongoing Federal CARE Act program that is dedicated to youth. It currently provides small grants to youth programs in just five localities -- Boston, Chicago, New Orleans, San Francisco, and Puerto Rico -- although other communities have significant populations of HIV-positive youth.

HRSA's Special Projects of National Significance (SPNS), a Ryan White program, provides competitive grants to support the development and evaluation of innovative and replicable models of HIV care and services. In 1994, the SPNS program awarded \$2.7 million in three-year grants to 10 community-based organizations to support innovative models of HIV care for adolescents and young adults. Unfortunately, although youth projects are still eligible to apply for SPNS grants, there is no longer a SPNS component dedicated to adolescents and young people.

The programs most successful in getting young people into life-saving care -- and keeping them there -- respond to the unique needs of HIV-positive young people. Many offer "one-stop shopping" by integrating primary care, HIV specialty care, mental health services, case management, and other care these young people need. The number of such programs has grown somewhat since the 1996 report, as has the number of youth enrolled. However, the exciting HIV treatments that have emerged since then -- treatments that are helping young people live longer, healthier lives -- mean that more young people will be needing ever-more complex care. Many of these treatments are very expensive, have demanding regimens, cause severe side effects, require intensive medical monitoring, and can stop working over time -- all factors of particular concern for youth. As adolescents and young people with HIV live longer and require more complex medical care and support services, the demand for specialized care for youth will continue

to increase.

We must keep pace with that demand at the same time that we forge ahead with youth-specific research, as discussed below.

Research

The federal government supports a wide range of AIDS research including epidemiological, behavioral, medical, health services, and social science research. This research portfolio rests with numerous federal agencies, among them the National Institutes of Health (NIH), CDC, HRSA, the Agency for Health Care Policy and Research, the Department of Veterans Affairs, and the Department of Defense. Federal spending on AIDS research programs has grown from approximately \$1.6 billion in FY 1996 to \$2.1 billion in FY 2000. Although most of this research is not specific to young people, the expanding knowledge base about HIV benefits everyone.

Youth-focused biomedical and behavioral HIV research is helping to describe the nature of the HIV epidemic among youth, identify effective behavioral interventions to prevent HIV infection, understand the effects of HIV in young people, and improve treatment options. However, the research necessary to understand, prevent, and treat HIV and AIDS in adolescents continues to be a very small part of the overall AIDS research effort, and we still face many of the research gaps and challenges identified in the 1996 report.

Prevention Research. Several Federal agencies are supporting youth-specific HIV prevention research initiatives. The National Institutes of Health (NIH) receives the majority of funding for research, and convenes a working group to review the agency's perinatal, pediatric, and adolescent research priorities.

Within NIH, over 20 adolescent-specific studies are examining factors that lead to HIV risk behaviors, and over two dozen studies are developing and evaluating social and behavioral interventions to reduce HIV infections among youth. For example:

- The National Institute of Mental Health (NIMH) is studying ways to delay initiation of sexual activity and promote consistent practice of HIV risk-reduction behaviors. These include studies of adolescents recruited from STD and family planning clinics, residential settings, and school- and community-based programs. Interventions involving parents and other family members in HIV prevention are being developed and evaluated. Special efforts are being made to focus on homeless and runaway youth, youth of color -- including Native American youth -- and gay youth.

- NIDA is supporting studies on the relationship between substance use and HIV risk behaviors among homeless adolescents, HIV risks among young women who are injection drug users or sexual partners of injection drug users, and risk reduction interventions for drug-abusing juveniles admitted to court-mandated treatment.
- The National Institute of Nursing Research (NINR) is supporting several studies on behavioral interventions for youth, especially youth of color, such as a University of Washington study examining disease prevention beliefs and behaviors related to HIV and STD infections among Pacific Islander adolescents. Results will be used to develop and test a culturally sensitive adolescent health and HIV prevention program.
- The National Institute of Child Health and Human Development (NICHD) is studying HIV-positive youth and is combining medical monitoring with a prevention intervention. Another set of NICHD projects is investigating risk behaviors in middle childhood that might lead to risky sexual behavior later on, and researchers will follow the children until some are 24. Other studies are investigating the ways attitudes and sexual behaviors are influenced by romantic relationships. Still others are focussed on youth in foster homes and other high risk situations.

NIH disseminates HIV-relevant prevention research findings from its behavioral prevention studies of young people in a variety of ways. For example, NIDA has developed and distributed widely a guide entitled, "Preventing Drug Use among Children and Adolescents." It was designed to help local service providers find practical applications of research-derived prevention principles.

NIH also has major initiatives in vaccine and microbicide development. The successful development of these tools will be invaluable to the prevention of HIV in young people. NIH is recruiting young people into networks that will test these new prevention options.

CDC and SAMHSA also conduct HIV/AIDS prevention research. Among their current projects targeting youth are:

- Project SHIELD, a community-focused program that is developing and evaluating ways to reduce high-risk behaviors (SAMHSA).
- The Community Intervention Trial for Youth, which is developing and evaluating

a comprehensive, community-level approach to encourage young men who have sex with men, primarily men of color, to reduce HIV risk behaviors (CDC).

- Project START (STD and AIDS Reduction Trial), which is developing and evaluating innovative science-based interventions to prevent HIV and STD infection and transmission among young men in prison who are about to return to their communities (CDC).

According to the NIH working group, some of the unanswered scientific questions in the prevention area are:

- what influences family, social and sexual networks have on youth risk behaviors,
- how different approaches to prevention (e.g., STD treatment, promotion of barrier methods such as condoms, and promotion of microbicides when they become available) should be combined,
- why previous prevention strategies failed to work with HIV-positive youth, and what the experiences of these young people can teach us about targeting programs to high risk youth,
- how to identify the key ingredients in successful prevention strategies, and why some interventions did not work,
- and how to communicate this information to service providers who are tailoring programs for particular populations of young people.

Treatment Research. NIH also funds the Pediatric AIDS Clinical Trials Group (PACTG), a network of sites that conduct HIV research with children, adolescents, and pregnant women. In recent years, the PACTG has been developing protocols to help improve HIV treatments for adolescents and to simplify treatment regimens. The PACTG has also completed a research study to improve approaches for recruiting and retaining youth in clinical trials. In 1998, the PACTG launched an Adolescent Initiative, which provided seed money to nine research sites to develop and implement HIV/AIDS research protocols for adolescents infected through [their own risk] behaviors. Research goals include assessing adolescents' immunologic and virologic responses to HIV therapy and developing simpler, adolescent-friendly HIV treatment regimens.

The Adolescent Medicine HIV/AIDS Research Network was funded in 1994 by NIH to

create an infrastructure for AIDS research with adolescents ages 13 to 19. The Network's objectives are to: characterize the natural history of HIV in adolescents; resolve basic science questions about the susceptibility, infectivity, and transmissibility of HIV in adolescents; produce clinical management guidelines for adolescent HIV infection; and provide youth access to clinical drug trials. Two major Network initiatives are Project REACH and Project TREAT.

- Project REACH is an observational study of the biomedical, psychosocial, and behavioral aspects of HIV in adolescents. The project has enrolled approximately 350 HIV-positive youth and 180 HIV-negative but high-risk youth at 15 clinical sites across the country. REACH has already yielded much of what is known about adolescent-specific responses to HIV infection.
- Project TREAT is a new effort to respond to the challenges of helping adolescents effectively participate in complex treatment regimens. Project TREAT is developing, evaluating, and distributing a multi-faceted program to enhance treatment adherence. The project also has developed a monograph on adherence support for clinicians treating HIV-positive adolescents.

While Project REACH has helped identify the behavioral and psychosocial problems of HIV-positive youth, only a few NIH studies are testing interventions to address these problems. One such study, supported by NIDA, is identifying ways to reduce substance use and risk behaviors, increase health care utilization, and enhance quality of life for substance-abusing youth living with HIV.

This new youth treatment research infrastructure should be supported and built upon. The nature and scope of the AIDS epidemic among our nation's youth deserve increased attention. Among other topics, more treatment research with adolescents is needed on:

- the extent of HIV infection,
- the barriers to receiving care,
- the biological and psychosocial consequences of HIV infection,
- responses to HIV treatment strategies already studied in adults and young children,
- the long-term consequences of these treatments,

- and adherence to and simplification of drug regimens.

Addressing some of these questions will require even closer collaboration between NIH, HRSA, CDC, SAMSHA and other federal agencies than has taken place in the past.

Recommendations

Many of the specific action steps recommended in the first ONAP report to the president on HIV and AIDS in America's youth have been taken over the last four years. This progress reflects the Federal commitment to our nation's youth, as well as the brain power, energy, and hard work of our researchers, care providers, local governments and communities, neighborhoods and families. Regrettably, however, some things have not changed. Young people still represent half of all new HIV infections in the United States. The Federal programs that provide care and support to youth affected by HIV continue to be too small in scope or too narrow in vision to meet needs that have been apparent for years. As illustrated by some of the recommendations that follow, there is certainly more to learn, but the time has come to apply what we do know on a large enough scale to make a real difference. The following recommendations outline a plan of action in the areas of HIV prevention, care, and research.

HIV Prevention

The federal government should develop a three-year coordinated national plan to prevent HIV infection among young people, particularly those who are at highest risk for HIV infection.

We must continue to identify gaps in current HIV prevention efforts and develop and implement a three-year coordinated national plan to close these gaps.

The President should designate a high-level point person within the Department of Health and Human Services (HHS) whose responsibility it will be to make sure a National Youth HIV Prevention Plan is developed and carried out. An effective plan will:

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

At the request of CDC, the Institute of Medicine (IOM) is conducting a comprehen-

sive review of current HIV prevention efforts in the United States. The IOM has been charged with proposing a visionary framework for future national HIV prevention strategies, based on this review. The IOM's final report, due in July 2000, should be used to help inform a National Youth HIV Prevention Plan.

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

- The Federal government should find more effective ways to encourage researchers and community-based HIV prevention service providers to work together.
- 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, and other decisions makers, and to advocate for the adoption of effective HIV prevention models.

The Federal government should significantly increase funding for youth-focused HIV prevention, particularly prevention that targets youth at highest risk for HIV infection.

Echoing the disparity that prompted the Minority AIDS Initiative, funding for youth-focused HIV prevention programs is disproportionate to the estimated infection rate among young people and insufficient to halt the spread of HIV in this group. A major increase in Federal funds for youth-specific HIV prevention activities is essential.

- A substantial amount of new funding should be allocated for and directed by CDC and SAMHSA to addressing the most critical needs identified in a National Youth HIV Prevention Plan.
- Prevention service providers receiving this new funding should be held strictly accountable for adherence to best practices as identified by prevention science.
- In addition, Federal agencies should use existing resources to expand youth-specific initiatives.
- There should be a review of public sector and private sector programs at all levels to determine how science-based HIV prevention activities can be more fully integrated into ongoing programs and systems that already reach young people.

- All federal funding for HIV prevention among young people should more equitably address the needs of youth at highest risk for HIV infection, including youth of color, adolescents and young women in high-risk circumstances, adolescents and young men who have sex with men, youth who engage in substance abuse, and homeless and runaway youth.
- As part of a multi-pronged prevention strategy, STD screening and treatment should be supported at a level that makes it available to all young people.

A relatively large amount of Federal resources has been dedicated to abstinence-only education programs. Thus, priority for future funding increases should be given to comprehensive HIV prevention programs that address the needs of sexually active young people.

The quality and availability of HIV prevention programs reaching youth in schools should be improved.

HIV prevention education must be fully integrated into comprehensive school health programs that address the full range of public health issues affecting youth, such as unplanned pregnancy, violence, sexual health, STD prevention and treatment, and substance abuse prevention and treatment.

- CDC should do more to support and promote comprehensive health education and HIV prevention programs in the nation's 15,000 school districts.
- Schools should enhance the prevention services they provide to high-risk youth, consistent with priorities set by local community planning groups.
- CDC should expand training and support for collaboration among community planning groups, state and local education agencies, and youth-serving organizations. In addition, the National Youth HIV Prevention Plan should include specific steps to improve coordination of school-based HIV prevention activities, both within CDC and among Federal agencies.

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 among youth, on a similar scale to the

remarkably successful public health effort to reduce HIV transmission from mother to child. This initiative should be a component of the National Youth HIV Prevention Plan and should build upon existing Federal initiatives to prevent HIV infection and promote counseling and testing.

Significant new resources will be necessary to fund this initiative, which would have as its goal increasing the number of at-risk youth who seek HIV counseling and get tested and the number of HIV-positive youth who are diagnosed and linked to comprehensive care. Among the initiative outcomes:

- voluntary HIV counseling and testing should be a routine component of adolescent health care;
- HIV counseling and testing sites, including those funded by CDC and HRSA, should be expanded to reach all youth at risk and should become more youth-friendly. That is, they meet the developmental and emotional needs of youth and are tailored to the culture and language of youth at risk;
- HIV testing sites and programs have strong linkages to youth-friendly care and treatment facilities; and
- social marketing campaigns and other strategies to educate youth about HIV counseling and testing should target all youth at risk of HIV infection.

The Federal government should take the lead in encouraging 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 and other adults. Providing this level of support is extremely challenging. Meeting the challenge requires realism, hard work and commitment from our nation's government, civil institutions, neighborhoods, and families. Young people, parents, and all levels of the public and private sectors have a role to play, but the Federal government must provide leadership as well as support for a coordinated effort.

Care and Treatment

The Federal government should seek to ensure that all HIV-infected young people have access to comprehensive, community-based health care that

addresses their medical and psychosocial needs.

The Federal government should expand efforts to enroll youth who are currently eligible for CHIP and Medicaid into these programs and 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 CHIP.

Medicaid coverage also should be expanded to cover all low-income people living with HIV, not only those who qualify as eligible because they have an AIDS diagnosis, as is true under current policy. This is particularly important for HIV-positive young adults over age 18, who do not qualify for the CHIP program.

The Administration should build on the Ryan White CARE Act as a central component of the health care safety net for youth affected by HIV and AIDS. Federal legislation that authorizes the Ryan White CARE Act is set to expire in September 2000. The President should support reauthorization of the CARE Act, including Title IV. The reauthorized legislation should ensure that programs funded under all titles of the Act are more accessible to youth.

Ensuring that existing safety-net programs meet the needs of HIV-infected and at-risk youth will require a major national initiative. As it stands now, only a small percentage of federal AIDS resources is targeted to youth. The President should request increased funding for the Ryan White CARE Act Title IV Adolescent Initiative in order to provide resources to communities that have significant populations of HIV-positive youth but are not currently funded under the initiative. New funds also are needed to support evaluation and quality assurance for these programs and to build permanent service links between substance abuse, mental health, family planning, and adolescent primary care programs.

For youth living with HIV/AIDS, housing is an essential component of comprehensive care. Young people are more likely to follow the complex treatment regimens that offer so much promise if they have stable housing that provides a reliable address where they can be reached by care providers, a safe place to keep medications, including refrigeration for those drugs that require it, and other necessities that many of us take for granted. Because HIV-positive youth often lack stable housing and have difficulty using housing programs, HUD should examine ways to increase access to Housing Opportunities for People With AIDS (HOPWA) programs for youth, especially young adults ages 17 to 25.

The Federal government should expand and strengthen training and technical

assistance for HIV service providers and youth service providers to help them respond to the unique needs of young people living with and at risk for HIV/AIDS.

The Federal government should provide major additional funds for national youth and HIV training and technical assistance programs to train service providers to better respond to the unique developmental and psychosocial needs of young people living with and at risk for HIV and AIDS. It is also necessary to recruit and train more health care providers to treat young people with HIV. One possible approach would be to create incentives within the National Health Service Corps, such as scholarships and loan repayment programs for health professionals who commit to working with adolescent HIV care programs.

Now that the Special Projects of National Significance (SPNS) program no longer has a dedicated youth component, HRSA should continue to fund a significant number of youth-focused projects within SPNS in order to develop and disseminate innovative models that respond to emerging issues in adolescent HIV care.

Research

The Federal government should develop a coordinated, comprehensive research agenda on youth and HIV/AIDS.

Although research related to HIV and youth is being conducted by a number of different federal agencies, no mechanism currently exists to identify research gaps and to minimize duplication of effort.

- 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 epidemiology, prevention, and care and treatment, and it should direct the allocation of youth AIDS research funds within and among federal agencies.
- In addition, the Office of AIDS Research (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.

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

As discussed in the Prevention Recommendations above, CDC, NIH, and other Federal agencies that conduct AIDS research should expand efforts to ensure technology transfer -- the translation of research results into practice.

The federal government should devote significant new funds to adolescent-specific AIDS research.

This recommendation continues the 1996 recommendation that "adolescent-specific biomedical and behavioral research should be increased to enhance our knowledge of the progress of HIV disease in adolescents and of effective AIDS prevention approaches."

More adolescent-specific biomedical and behavioral research is needed in the areas identified by the NIH working group. There is also a need for research regarding:

- rates of HIV infection and risk behaviors;
- the level of unmet need for services for high-risk youth;
- the determinants of risk behavior among specific youth populations, such as youth of color, adolescents and young women in high risk circumstances, adolescents and young men who have sex with men, and homeless and runaway youth.
- new multi-level intervention strategies for high-risk youth, and how to tailor existing approaches to address the needs of specific cultural and risk groups;
- prevention service coordination, cost effectiveness, planning and delivery;
- structures and policies that serve as barriers to the delivery of evidence-based prevention programs for youth, and ways to overcome these barriers.

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.

NIH, CDC, HRSA, and other Federal agencies involved in AIDS research should enhance youth participation in this research.

NIH should promote access to research opportunities for HIV-infected young people by providing incentives, training, and technical assistance to improve enrollment of youth in the Adult AIDS Clinical Trials Group (AACTG), Pediatric AIDS Clinical Trials Group (PACTG), and Clinical Programs for Clinical Research on AIDS (CPCRA). NIH should take similar steps to recruit, enroll, and retain young people in research studies on preventive HIV vaccines. Special attention must be given to increasing participation by youth of color. All NIH AIDS research sites should document steps they are taking to enhance youth participation in studies and to gather youth opinions and counsel.

Institutional review boards should take steps to reduce barriers to youth enrollment in research. Currently, some unnecessarily require parental permission for youth participation in AIDS research. Review boards should be encouraged to review their procedures in light of the *Guidelines for Adolescent Participation in Research*, produced by the Society for Adolescent Medicine.

NIH, HRSA, and other Federal agencies also should ensure that health care providers who work with HIV-positive youth are better educated about AIDS research opportunities for youth and effective strategies for helping them gain access to these opportunities to participate in research.

CONCLUSION

In 1997, President Clinton reminded the American people that youth is a time of opportunities and risks: "The choices that young people make during these years profoundly affect their chances of becoming healthy, responsible, and productive adults." Three years later, at the White House Conference on Teenagers: Raising Responsible and Resourceful Youth, First Lady Hillary Rodham Clinton echoed those sentiments: "We're all worried about the choices our teenagers make, about how the best-laid plans for a bright future can disintegrate with a single bad decision to drink, to try drugs, to drive too fast, to trust the wrong person." The First Lady went on to challenge Americans to discover innovative ways to ensure that every teenager has a safe passage to adulthood.

A safe passage into a healthy, responsible, productive adulthood -- this is our dream for our children. But, as William Butler Yeats challenged, "in dreams begins responsibility." Timid hopes for the best are not enough. We must all take action. Families, businesses, communities, and government must come together in coordinated efforts because young people have a right to depend on us as adults. We must mobilize our nation's resources -- unparalleled in American history -- to protect our young people from the ravages of AIDS, from the consequences of decisions made too young, and from burdens too heavy to carry alone.

Today, four years after the first report to the President on youth and AIDS, we see too much complacency about matters that should shock us. We forget that disease statistics represent real young people who are just starting their lives. And we are failing to take advantage of the opportunity to learn exportable lessons about prevention and care -- lessons that could help turn the tide in the global AIDS pandemic that has been declared a threat to our own national security.

Our hard work to date has created a growing arsenal of powerful weapons to use in the fight against HIV/AIDS in young people. We are in a position to inform, care for and empower our nation's youth. We must do so without further delay. It's time.