FOIA Number: 2018-0755-F

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Collection/Record Group:	Clinton Presidential Records
Subgroup/Office of Origin:	National AIDS Policy Office
Series/Staff Member:	Patsy Fleming
Subseries:	National AIDS Strategy

OA/ID Number:	10182
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Folder Title:
Brenda's Notes - Women & HIV Conference

Stack:	Row:	Section:	Shelf:	Position:
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WOMEN AND HIV CONFERENCE

Karen Hein: HIV Prevention and Care for Adolescent Women

Jackie Wilson/NCHS: Risk Behaviors and Effective Education - NCHS

NHIS - probability sample, in home, continuously conducted, non-institutionalized, basic health
-created approximate measure of head of household

The majority of adolescent women are exposed to AIDS education. Prevention must be aimed at multiple risk behaviors. Family structure and education levels affect.
Limitations:
-unable to determine content and amount of AIDS education
-no sex questions
-YRBS is a one time supplement so can't look longitudinally
-YRBSS is in school

Data is:
-geo coded to census tract - can associate neighborhood characteristics
-comprehensive in and out of school
-concurrent HIV risk, smoking and violence

Kim Miller/CDC: Partner Perception Strategies: Like Mother Like Daughter

Strategies for determining HIV status of potential sex partners
Safety scale:
-perceived similarity
-in-group status
-network recommendation
-perceived knowledge
Sexual contacts and partner characteristics - discussion comfort level
Can't assume parents know - Mothers may be providing erroneous info on partner safety

Bea Krauss/NDRI: 10 - 13 Year Old Girls' Prescriptions for HIV Prevention Conversations in their High HIV Seroprevalence Neighborhood

Anne Stermock/DCFP: Self Efficacy Interventions to Improve HIV Prevention Among Psychiatrically Hospitalized Adolescent Women

Impact self-efficacy:
-confidence during emotional times
sexual abuse history
infrequent condom use history

Donna Futterman/MMC & Audrey Rogers/NCHD: Compare Male and Female Demographics

50% of the new infections in the world are occurring in people under 25 years old WHO
NICHD - SAM Survey 1993
-vertical and blood routes of transmission are more likely to be receiving care than FSM or MSM
-7.7 times more likely; 5.4 times more likely if Tcells are under 500
-MSM and IDU and older teens are associated with the likelihood of getting treatment
- marks of support system, stability
-women 72% partner of unknown serostatus; men 82% MSM

Donna Futterman: HIV-Associated Risk Behaviors in Adolescents

Michael Danovsky/RIH: Psychiatrically Hospitalized Adolescents: Sexual Abuse as a Co-Factor in HIV Risk

Increase in sex, self-mutilation, drugs
No seroprevalence studies: .2% to 2.2%
Issues for these teens: diagnosis, cognitive impairment, risk assessment, impulsivity, self-esteem, lack social supports, and financial stability
? - 6% females, 3 331% males
One-third of psych hosp adol were sexually abused
Few transmissions by perpetrator; most by increased risk behaviors after abuse
NIMH funded research: psych hosp adol are more likely to use drugs, have lower self-efficacy, lower condom use, and endorse risk taking

Meg Doherty/JH: Circumstances of Women Initiating IDU

REACH - a CDC funded program
-71% new AIDS cases are IDU in Baltimore
-less than 2 years of injecting, less than 20 years old, history of STDs
-most had first time companions that were a female friend; not a male sex partner
-women got more public assistance; men were more likely to get money through illegal activities
-women's illegal source of money was prostitution, men's more likely to be drugs

Linda Valleroy/CDC: HIV Seroprevalence Among Disadvantaged Out-of-School Young Women

Job Corps 1990 - 1994
HIV 2 times higher in women at 16 years of age; only at 19-21 years old were women and men closer in range
Highest were in 16 to 17 year old African American women from the south
The numbers declined from 1990 to 1994

Karen Kelley/NYDH: AIDS Among Adolescent and Young Adult Women in NY State

Ratio of men to women is dropping
Among the youngest teens there are more women than men and more likely to be heterosexual
One-third IDU; older adolescents are more likely to have IDU source
AIDS defining similar: 1st = CD4 count; 2nd = PCP; 3rd = TB
African Americans most likely to be infected
Need to address risk reduction before IDU and sex initiation
Unusually high TB rates in young people

Tom Nattel/NYDH: HIV Prevalence Among Homeless and Runaway Females in NY City

CDC; blinded seroprevalence from syphilis serology; 1987 - 1993; 17.9 year old mean
5.3% in 1987 and 7.5% in 1993 for young women
Seroprevalence is going down but there are now parallel providers
Young women are more likely to be infected than young men
Women in and out of school have high rates of transmission
Men have low infection rates for those in school and high for those out of school
Implication is that women are being infected by older men
Ease of acquiring for women IDU

Adolescents & AIDS Meeting
David Harvey, Janet Shalwitz, Mildred Williamson, Alicia beatty-Tee
December 16, 1994

The report:
format = statistics, federal accomplishments, future role for feds, future role for others

1. What are the issues that you think should be included?
   What statistics/trends would you highlight?
2. What should the framework/underlying theme/message be?
3. What's your perception of Federal programs/policies? CDC, HRSA, SAMHSA,
4. What do you see as the state/local governments role?
5. What do you see as the nongovernment role? Do you distinguish non and for profit?
6. Process: Do you have suggestions for organizations/people that should be consulted?
   What would you consider key questions?

Meeting Summary

The report should state that good work has been done and point out successful communities. Phrase needs as building from a base.

The report should reflect the need for holistic youth services. The education, criminal justice, violence prevention, welfare, etc. systems should be involved in the focus groups - in addition to the researchers, service providers, adolescents, families and feds.

What could the President do that would have the greatest impact? Going into the field (vs. White House based) would be the best. Perhaps HIV could be part of a larger youth initiative that the President undertook to capitalize on the need for integrated service systems. Need a marketing strategy.

HIV among adolescents looks different than for other age groups and is looking different than it did a couple of years ago. HIV+ adolescents are more likely than adults to be in marginalized groups - i.e. to be abused or abusing or to be choosing alternative lifestyles - and to lack resources. Over the past few years, HIV+ adolescents have become more likely to have been infected through sexual transmission than through blood or from their parents.

Possible partners for focus groups: SAMHSA, NIDA, NIMH, DASH, Kaiser, Robert Wood Johnson. American Public Foundation, the Annie C. Casey Foundation and the Wellness Foundation have not traditionally funded HIV projects, but they may.

Followup with a letter requesting: names and organizations for the resource list; key questions to be asked for focus groups (general as well as targeted); opportunities to add a focus group

Meeting with Abigail English: 4/7&10

Areas can talk about:

Young Mothers	Status of States	Research	Instituitional
Linking Testing & Tx	Military	Juv. Justice	

expertise: consent, comfidentiality, financing, partic. in research, discrimination

Young Mothers-sending copy of comments
- -issue because epidemic spreading rapidly
- -concern access to prenatal care, early counseling access to range of follow up care

Testing and Counseling better own section than in prevention- would like services

Mandatory testing- military, job corps
- * least helpful way to receive info
- * physicians- Job Corps- not given referrals
- * call back v. letter later
  - -unable to complete physical need to comeback
  - -can do counseling with referrals
- *do they take people with TB? if so, why not PWA?

Juvenile Justice and Instituitional
- -mandatory testing in JJ- wide variation in testing & confidentiality of results
- -LA- test all young people in facility- not involuntary informed consent but essentially all tested. shared with outside medical clinic b/c statute in CA requires head of facility be informed. Research protocal provides exceptions
- -emphasis should remain on voluntary testing, universal precautions, preventions (difficult to give condoms when sex is against policy)
- -testing at entry not adequate b/c 6 month window and sex in facility

Key Messages:
1. no overriding reason to abandon voluntary testing
2. don't tailor policies around belief that they can test and know status-need to do universal precautions and prevention work.
   - -discrimination- residential care facility want to know status or cannot admit
   - -can't serve purpose of staff
   - -delusion that can get this info

Consent framework- some blanket as if can do STDs can do HIV
- providers concern: more weighty implications than STD
- technical legal standpoint- not every state would cover
- some states specified minors and HIV ok or testee can ok regardless of age
- some states specified HIV as a VD or STD
- some states specified as communicable/ infectious
- some specify testing only; some also services or services if homeless or parents

Reasons at risk = reasons don't want to risk disclosure so consent important
Treatment- only for that specific HIV test.
- adapting fed. guidelines to research accessibility.
- Need support of adult but shouldn't be prereq.

Notes:
contact: Alice Eisenberg

Resources
-transmission women to women
-non- Spanish speaking language
-battle of stats

School Board
-trends and stats must be totally in our favor
-less than 95%- can't use

lack of info.
Use youth
Speak out to tell people about their experiences

New York City Public Schools
* Funding- programs- services
gov't red tape
Ryan White
State red tape- can get around
federal red tape- can't get around
7 kids a day infected in public schools
talks about condom use and demonstration

can't happen to me syndrome

-unsafe sex even when you know the facts
-getting communities involved
-don't make sex seem dirty- it's ok
-but need to look at reason why they're not using condoms
-increase in AIDS funding
-counseling*
-stigmatization of sex
-education
NO ADULTS in the room
bring in people who are affected
peer, not just teen to teen
-prisons- incarcerated youth
-encourage education in and out of school
-educate peers outside and send them back to be peer educators

Bureaucratic red tape
-ordering condoms
most effective

mother to fetus transmission
teen pregnancy
076- drug trial number
-adolescent provider in community
-treatment
-red tape in Medicaid for adolescents and lower income communities
-broad range so everyone can identify with someone
    -key message*
    Concentrate on prevention within different communities
    -studies on youth that are affected
* community/age appropriate reports and info.*

prevention:
    transmission through semen, vaginal fluid and blood
community specific language
- 2 versions
-find groups that can translate before we release it
-format- don't put cure first
- don't equate death with AIDS

Worst thing we could do: basing it on abstinence

to other efforts (conferences, e.g.).

Issues to address:
the impact of coercion, i.e. older sexual partners;
the need for outreach in a nontraditional ways to nontraditional youth;
the impact of managed care on providers ability to do right by young people;
problem of high infection rates due to the lack of explicit messages;
pregnancy and HIV are gold cards into any service system;
service system still geared toward delinquency prevention;
umbrella organizations like schools and YMCAs are either overcrowded or going under;
clergy are a source of contact that need to be tapped;
encourage communities just beginning to plan;

Get accurate/real numbers, dollars from Title IV, SPNS, NIH. Ask programs what anecdotal differences they are seeing between this year and last year. Get update Job Corp data.

How does forming linkages with Republicans play into the strategy?

Resources:
MTV folks Stormi Chavez Nat'l Hx Grantees/NIH/Audrey Rogers
Larry DiAngelo

AID Atlanta
May 16, 1995

Present: Joe Wright (gays), Maria Rivas (Hispanics), Craig Washington (African Americans), Jody Libo (youth), Jane Carr (Executive Director), Richard Sowell (PhD, RN, Women's prevention case management)

1. Highlight the successes regionally.

2. Perception is that there are no gay youth. In Georgia, there is an exodus to Atlanta. Gay youth have unique needs.

3. Too many needs assessments, no product. Difficult to do n a.

4. Sexuality across the board needs to be open for discussion. Communication should be open.

5. Skills needed. Look at STDs and pregnancy rates.

6. School boards are how education gets into schools.

7. Holistic approach - self esteem, role models should be made available.

8. Metro Foundation Atlanta. Gay youth and parents get affirmation. Help parent's reinforce positive self-image/attitudes. Atlanta Executive Group has made this their project. Reshaping family values. Specific message is needed. Can't use "gay youth" because they don't use labels.

9. For the Hispanic community from Mexico, there is a norm of men having sex with men as a rite of passage then most move on to women. Young Hispanic women are so naive. They need to be assertive, learn communication skills.

10. Must do under the table. Even if churches/governments can let slide, one powerful person can pull the program.

11. National and regional statistics. Number of Hispanic children is greater (proportionally?) than the number of white children. Approximate age of infection - do the ten year thing. These help legislators know their youth are at risk. Age of first sex, teen pregnancy, STD rates and links. Syphilis and HIV epidemic link, especially in very rural areas.

12. Report: consistency in message. Schools need to dealt realistically with sexuality. Press coverage that reflects the moderate gay community. Highlight things that were tried and have worked. Some people will never buy in.

Ask Us
AID Atlanta
May 16, 1995

1. Lack of education is a big issue. Often can't get in to schools. School boards and parents need education. Adults aren't educated and refuse to believe what's going on. They lived in a different time, HIV wasn't there. Everyone says not me, not my job, I'm not trained.

2. Educate parents. Stereotypes live on in parents. Biology textbooks are inaccurate. Need to correct information one on one. After peer education classes get a lot of people asking questions, telling their stories one on one - students and teachers.

3. Talking to Teens is a parent education workshop that uses skits, talks about body language. Arose out of the constant barriers we faced. Doing a preliminary meeting with parents got us an entrance into the school. Need to assessments/evaluate, don't assume what a community is like before you go into the schools.

4. Get people, especially in religious groups, who assume that if you talk about sexuality that you are promiscuous.

5. Parents range from denial to expecting that their kids will have sex, do drugs. Assume that if kids are educated about sex, they'll start having sex.

6. Risky behavior for teens is the same as for adults.

7. Sex education and HIV education should be linked. Professionals versus gym teachers should be giving the classes. Most gym teachers don't talk about the emotional or social pieces. It's an easy "A" class. Needs to be personalized. Talk about what can happen if you have sex. Alcohol and drugs lead to sex. Same thing is happening in public and private schools.

8. Rec: early education by the sixth grade. Earlier, depending on age/appropriate. This shouldn't be foreign to a kid at 12 years old. Found that students range from know it all by the time they learn it to completely ignorant and what's presented is over their heads. Some parents never talk about it, others are good at it.

9. Rec: condoms should be available. Educate school boards. Now expelled if you distribute them.

10. Rec: need to listen to us. We're not all generation X. "Oh my god, this is so tragic!" is not the response we need. We need action. We do have a voice, knowledge, can think. We're not all sexually promiscuous. Check it out, ask us. Try it out, don't assume what we'll say.

11. Rec: breakdowns, by groups, increases disinterest to something, becomes "them".

Meeting with Audrey Rogers: 5/22

Research Network

- -research agenda set in Chicago 2 years ago
- -CDC
  - -no longer doing adolescent clinic for seroprevalence
- -ask Audrey re: slide on HRSA
- -NIH NIAID
  - fundamental discoveries:
    - lab based immunological, viral
    - clinical trilas
  - expand knowledge base
    - theory based behavior
    - population-based

HERS study

Adolescent
- -early adolescence infected at birth
- -blood transfusion
- -hemophilia
- -drug use, survival sex
- -sex

Need to know
- -behavior-qulaity/quantity, sexual initiation

Physiology
- -immune development during pregnancy
- -mucosal immunity and infectivity
- -cervical ectopy and susceptibility

For HIV youth
- -What look like and where are
- -state case HIV vs AIDS
- -serosurveys
- -how growth order throughout adol. is affected
  - neurocognition
  - physical growth spurts
  - menstrual patterns
  - psychosocial and emotional state

Teen preference- anonymous
- confidentiality is key

How HIV develops
- -comorbidity with other STDs
- -cofactors HPv. smoking, herpes, CMV
- -concurrent conditions: drug use and pregnancy

What conditions develop
-spectrum (Ped or adult)
-incidence and prevalence of conditions
-clinic predictors of conditions

Cross Cutting Evaluations

Data collected from 11 sites to get comparability in conclusions

Ability to have current information

Younger men getting wider range of services than younger women. Men more intense higher skill level. Women -emotional, jobs discuss

Conference

Continued funding
Titke 1 treatment may not be appropriate since data show only 15% HIV+- may be more prevention/ CDC territory

?- when research SPNS clients- HIV+ not in a care
unethical do many tests w/o youth receiving care
to get results need to know will get data over time-if don't get results, waste of money

Anecdotally hearing that CD4 counts drop rapidly, ??? burden peaks then CD4 drops

How do HIV+ youth get care
-barriers
-utilization of sero by
* perceived needs
* knowledge of existing resources
* number of contacts
* types of service
* type of provider

How to best monitor HIV infection
- optimal schedules for screening examinations
-systematic evaluation vs. symptom driven
-what clinically feasible combination of tests indicates true status

Consent- Title IV restricts

How Policy impacts

HR1271- Title 4 Contract with America
Family Privacy Protection Act

Minors- written parental permission
-surveys on: family beliefs, incriminatory activities, sex, relationships, psycho-emotional, privaleged relationships
-protect youth, protect integrity of family= guise for doing
Exceptions
-criminal investigations, health- welfare of individuals, INS, IRS, financial AID

Make instruments available to public
MAke these provisions known

12 Clinical Sites: LA, New Orleans, Miami, Birmingham, Atlanta, DC, Baltimore, Philadelphia, Chicago, Bronx-Monte, +2 in NYC
Clin. Sci Grp- Basic Sci. Group

Youth Suicide # increase CDC
link to prevention b/c HIV is probable cause

From Community Meetings
-use grandparents as a source/AARP
-barriers section
-concern that abstinence equals morality
- talk to teens, hemophiliia foundation

From Sheri Saltzberg
-way to access is provide a range of services as a way to engage
-importance of youth development- job training

Dan Daley
SIECUS
May 30, 1995

Participants: Dan Daley, Lisa Da Valle, Jerry Atchinson, Katie Smeltz, Brenda Kunkel

1. All adolescents are or will be sexually active. Once active, socioeconomic status determines access to health care.Serve all adolescents' needs.

2. There's an increased timespan of transition to adulthood.

3. Quality and content of sex education are critical recommendations/action steps. SIECUS has a state by state report.

4. Focus on schools = underutilizing other service agencies and intimidate other consumer groups from offering services.

5. The Office of Population Affairs and the Adolescent Life Act. Supposed to be about teen pregnancy, but has been nicknamed the "Chastity Act". Sex Respect and Teen AID, eg.

6. Far right is posing legal challenges to peer education.

7. Needs assessment will get a community buy in.

8. (Unsafe) sex is a rational decision from the perspective of the young person, even if s/he didn't like the consequences. Idea for after explaining the norm continuum, for talking about what comes into play on unsafe decisions.

9. Mobility. Teens go places (away from home area) to cause trouble/experiment. Youth are not likely to be hanging out with their parents' friends' kids; different peer group identity. No lifelong friends.

10. Older - younger relationships.

11. Community adolescent health.

12. Media. Don't distinguish bad judgement and pathology from sexuality. Makes it hard for youth to distinguish what are the tasks in an intimate relationship. Link intimacy with substance abuse and violence. Expand the definition of media to include things like putting a condom machine in a clothing store.

13. Educate the field pre-release.

14. Approach for parents: what was it like for you?

David 11/21

focus: lit review, major recomendations
-gear toward implementation vs. study
-analysis of rec already implemented from report
-areas needing further attention
    ONAPD Action Steps for impl.
-prioritize recs and our steps
-relate to our role and adv cncl and task force
-DH mailed PF a copy of commission
-analysis of most recent Cong. adolescent action
    1. Lab/HHS report language for adol.
        Jeff has copy
        pre RW- youth cntrd HIV care should be expanded
        titles and TA
    2. CDC Comm. Prev Planning
    3. NIH language cite so that show we are on top of most recent
-Programs
    -status of RW and impact on adol.
    -assess what RW really doing around youth
    tie to what's known on epidemiology
    2. NIH- youth in clinical trials
        youth funding cut, say some in adult
    -access to Audrey Rogers NICHD adol res network Title IV care
        and din trial sites
    3. Prevention- planning Initiative- are youth on council ?
        reaching highest risk; strategies working
        Marketing initiative

Use for Ryan White ???
    -show how RW improved to help young people
    -look at last year's bill and youth changes
    -title I youth councils
    -II- redefined family center and added youth center HIV care
    -II cross title planning process to analyze unmet needs in
        ast, plan, allocate
    -II new planning process- includes prov serv for women,
        children and adolescents
    -III no changes rec
    -IV move demo money included chil, youth fam language
        -coordination care and research
        -orphaned ch youth (powerful)
        -kinship care ch welfare

recs may reflect needs for epidemic

11/29- HIV testing maternal and HIV
12/5 & 6 HRSA 1st degree need gay/lesbian kids
12/15 & 16 HRSA cross title collab BOWEN
-coordinates our recs and comm

-HRSA AIDS advisory comm RW rec
-GAO study on RW briefing 12/2
-CDC coop agr NEA

strategy Rep offices take ownership

Pediatric AIDS awareness week- broaden
Public Policy Conference- late April

1. How do we care
2 Prevention, why failing

Kaiser Family Foundation

Rea 11/22

Status Report
Been
Who's going to do it
    -rec who best to do
Highlight what has happened and how existing avenues can be used

Carlos and focus groups
    -use exisiting information

National Network of Runaway and Homeless Youth
    Video based study Cynthia Jorgensen
    CDC/ NAIEP

TRENDS:
*Youth serv prov intentional infecting to get services or to suicide
*gay youth
*subculture- gay youth who want to be HIV+ to belong
* mental health issues of long term
* people who aren't infected and interaction with those who are
Clinton Anderson, Am Psych Assoc

Advisory Group
    to get people to carry out rec
    -acct

Lesbian and Bisexual Women
- getting pregnant to prove not lesbian- often by gay peers
-lesbian mentality- can't get HIV no matter who having sex with

frame in terms of sexuality

talk about someone's story
    National Assoc PWA have young people's speakers bureau

FROM DEMETRI MOSHOYAANIT 11/23

-what message were given to youth in previous studies/programs
-recognize spectrum of youth and their understanding of HIV (can't do 1 message)
-recognize 100% time safe sex not realistic-message shouldn't precipitate failure/give up
-adol. sex = mature adult if sex= condom and condom= uncomfortable and undesireable than adol. resent not being able to look forward to adult sex (range of intimacy response)
-testing:age limits; give youth sense of control over the situation
-youth need something to look forward to: if youth= value why live past 35
-nothing is geared toward HIV+ youth
-inevitability vs. invincibility for gay youth

-Previous docs/studies- their recomendations and what messages
    they've sent to young people
-prescriptive
-100% safe 100% of the time- achievable resources and knowledge
-institutional barrier
-spectrum- don't know safer sex
    others sick of message
-feasible to get 1 message out given
    unique needs- people would say doesn't
-difficulty bringing up condom usage
-dangerous- individ. responsibility tactic
    -comm. resp (hard young people)
-circum. don't always mesh with what's out there
-artificial categories separate birth control and STDs
-campaigns that say- may not be comfortable but do it
-resent condoms only answer resent grow ups so never experience sex without latex
-psych harmful messages
-power dynamics of younger-older relationshio communication skills
-testing age limits-go through pre and post counseling session
-give young people feeling that they have control over the situation and the decision
-NY Times article adol. and refusing treatment
-balance need for control with realization that they're not in a vacuum
-something to look forward to youth/beauty centered, why live past 35
-nothing geared towards HIV+ youth
-inevitability vs. invincibility for gay youth
-young people HIV+ need to talk to HIV-
-increase comfort for disclosure and ability to be okay with dating only HIV+ or HIV- people
-Corp National Serv
    want to be on interdepartmental task force

-Feb 19/20 Metro TeenAIDS Conf bringing in 250-300 young people
-NAtional Assoc of Positive YOuth conference in March

Demetri 11/23/94

-previous doses/studies--their recommendations & what messages they've sent to young people
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-HIV+ young people need to talk to HIV- young people
-increase comfort for disclosure and ability to be OK with dating only HIV+ & HIV- people
-Corp Nat'l Serv
    -want to be on interdepartmental task force
-2/19 & 2/20 -- Metro Teen AIDS Conf.
    -bringing in 250-300 young people
-Natl Assoc of Positive Youth, conference in March

Meeting with George Walter NAPO January?

comm access comprehensive pregnancies

will and sex

teen pregnancies

controlled copies

relative risk factor

kissing-anal sex

Coop's first report on HIV 1986, 1989

Link to teen pregnancy national strategy

Background risks how change

teen counselor on ACTUS hotline with alt for religious

They may have a first meeting by May

Jim Marks leading these efforts

Grady Hospital
Atlanta, Georgia
May 16, 1995

Participants: Ko Hassan, Phillip, Jackie.

1. Peer education for at risk youth and access to primary care are the two most important things. Usually lump adults and pediatrics. Long term 1:1 counseling is needed for hard to reach, vulnerable youth. Age range 10 - 25.

2. They do teen outreach on the street, in malls. Get a better response than in a structured environment. Can use real world language.

3. Their experience with Job Corps: JC disclosed HIV status to family members, sometimes before telling the youth. Poor confidentiality. Youth don't know their rights and don't follow up legally.

4. Disturbed that the Black Caucus signed onto the Ackerman bill. Their experience is that 95% consent voluntarily. Need to guarantee services and that they won't lose their jobs.

5. Teen consent rates are at 98%. Regional finding. In New York they tell youth of possible impacts of being found positive including loss of housing, rejection. Lack staff to follow up with youth who don't come back for results.

6. Physicians are not clear on teen rights and break confidentiality.

7. Pulling trains = drugs and group sex. Youth fear isolation. Need for a prevention place.

8. Youth have no knowledge about health. Practical issues of getting services, eg transportation. Concern that kids insurance report would go to parents. Or parents afraid that insurance companies will kick them off or employers will do something.

9. Self esteem and survival sex. Can't let go of the safety net. Youth can filter into the system through various categories.

10. There are protocols requiring parental consent. Need access to ACTG without parents.

11. Ryan White allows providers to offer a system of services; otherwise they'd resort to emergency care. RW doesn't keep up with the service needs.

12. Teen housing issue. 19 year old, HIV+ is put in with a 40 year old recovering addict. There's no housing for full families. Maslow's hierarchy.

13. Concern that with the climate of personal responsibility in Congress today, they'll view youth as responsible for the sex actions and therefore at fault for being +.

14. Include cost figures. ER is more expensive than outpatient Prevention money spent per person versus caring for one HIV+ person.

15. Youth know they are at risk, but couldn't didn't use prevention. Self-esteem, education, given no or wrong information. Youth education program in San Francisco.

16. Teens have nothing to do. No outlet. Even if no high risk background. Cruising is a set up. City council are responsible for this programming. Atlanta freaknic = college kids, young men disrespect young women, youth are respecting each other or themselves.

17. There's a level of hopelessness regarding drug use and condom use. Generation X = white middle and upper class kids are getting a sense of hopelessness. Not physical. No economic future.

18. Alternatives offered are too safe. Teens need to be involved in the programming. Need corporate buy in. Radio station buy in. Nike for example - where they spend money.

19. Rural problem. Huge rates in rural counties. Gay youth come to party. Young men party and commit crimes. They get no services, have no health knowledge.

20. Homophobia affects access to condoms.

Karen Hein
February 28, 1995

1. Division between youth services and medicine. Against testing because services not there. Adoption and foster care policies on testing - mandatory.

2. Job Corps and Military - mandatory. JAMA 1991 article: lawyer footnoted lawsuits. Military not given job and not given services.

3. Dependent minors of people in the State Department and Peace Corps - mandatory.

4. Sympathy framing, see as real kids. Relate to someone in their life.

5. Jim Wade - Kassenbaum. Alan Nissenson - Wellstone. Phil Marion - Bradley. Marion Ein Lewin - IoM fellowship program. Do breakfast with PF. Conrad Burns. Kristin Blake.

6. Political strategy: use middle America. get pillar of community to sponsor event. Do adolescents as a group and open to STD and pregnancy. Survival sex versus prostitution.

7. Condom availability. Involve youth, others in community. Kaiser Report "Condoms in Schools". use "availability" versus "distribution".

8. 076 orphans, long term survivors of perinatal. mention. Gay and lesbian youth - mention sensitive counseling and access.

9. Behavior at risk. Situations that make adolescents feel welcome. Noncompliance = provider problem.

10. Adolescent female physiology susceptible cervix, Phbase, progesterone.

11. NICHD multisite collaborative history. Audrey Rogers. Donna Futterman. Sten Vermont Lab. Barba Mojiski.

12. Clinical Trials - Adolescent working group. Donna F. Very few pure. Tracking things to see what it takes to get adolescents involved in clinical trials.

13. Society for Adolescent Medicine. Audrey Rogers. # in care with HIV.

14. Vast majority don't know infected.

15. Mike Mercen - half infected with HIV throughout world infected 15 - 24. WHO.

16. Calculate HIV infection via:
    a. Adults with AIDS and children with AIDS

b. Number of teens, percentage that are sexually active, STD markers, surrogate with HIV.
c. Take targetted seroprevalence studies and find out what percentage of kids are like these populations.
d. AIDS case data - iceberg ratio of the number of HIV+ : the number with AIDS.

17. Pitfall: cross tabulation on adolescents = eligible versus really in care

18. History of adolescent involvement in clincial trials. distorted history of the course of the epidemic.

19. AIDS case data difficult to capture if just have 13 - 19 year olds as range. Better to do 13 - 24. Denominator problem - chlamydia history per 100,000. For adults most have had sex. For adolescent if use all in denominator not representative. Correct = use numbers who have had sex. CDC doesn't like to do just those sexually active because it's inaccurate. Alan Guttmacher Institute report.

20. HIV serovprevalence - national: Job Corps and Miitary. Larry Di'Angelo - local. UN Development Program - Elizabeth Reed - one and a half years ago.

21. Jill Blair - NYC condom availability plan.

Phone Interview with Carol Levine

There is a vast literature on prevention and education
Karen Heinz is the school-based expert
Mental health, other barriers make minds shut off. Concern - we need to bring the whole world in.
Rural teens

Barbara Dramer - mental health needs of well adolescents. HIV+ family members causes teens to become overwhelmed and shutdown increasing risky behaviors. This runs counter to the idea that if they see it they don't do it.

Consent, ability to make decisions. Strengthen instead of underestimate teens. They are neither totally capable or incapable.

Concern for adolescents is waning because "my kid doesn't live in Harlem". Consider the extraordinary mobility of teens - they don't hang out at the same places or with the same people that their parents do.

How do we prepare kids for environments with risks when they are kept safe all of their lives.
Prevention often assumes that people are risk aversive - not true for adolescents.
Adol don't feel control over what happens to them
Adults must try to enter minds of teens
Adol don't have the message that symptoms don't show up for years
Adol know about HIV and how to prevent but have a sense of futility = will die anyway
Listen before you develop a prevention message
Long term process: start where the teen is and reinforce
Hard to evaluate the programs; know what in the community is supporting or opposing the effort
Delineate factors - ways to make risks higher or lower
Ratio young women is increasing; shown also in babies

Children are growing into adol with HIV+ and the numbers are decreasing on consensual sexual transmission

Need a section on health care availability. Barriers and range.

3 points: (1) parents are not convinced. (2) teens are not risk averse (3) different groups have different sensitivities

(1) Terry Lewis/NY grant development, parent advocacy group; PFLAG; Hetrick Martin; PTAs
(2) John Wright Save Face NY/Af Am youth
Andy Boxer - how teens think about the world
Michael Klatz ethnographer "street"
Len McNally fund,
Ruth Finkelstein - report, interviewed adolescents

NACYSO?

Adolescent Development

I. Section that segments groups
* should be targetted
*do a general section about youth- but by default straight youth take priority-Pay attention to gay, lesbian, & transvestites
*reason for breakdown, makes clear and more inclusive
*gives indication of effort
*specificity >best way to reach people is to know where they exist
*specificity will make them know that youth exist & are at risk to face a number of pressures
*young lesbians don't always understand magnitude of the problems ...
*what ever needs to be done to get funding -- if you don't specify people/ queer youth could be forgotten
*project staff should have skills to work with queer youth in the coming out process

II. What needs to be said to help support you?
*we exist, gay, lesbian, and transvestite youth
*funding needs to be in our hands
*measures are followed to existing structures that must take into account the need for funding for queer youth, ie Ryan White
**control of $ and programming - new model for organizational structures - needs priority youth advisory boards - establishment is issue (t.a. can help)
*sound out that y.o. can do Irun programs
*funding $ should so for skills building...appropriate training
*cooperate arrangements for agencies to work with youth and the funding channels create difficulty
*lack of services for Latino youth must be pointed out "functioning members of society"
*move past status quo--look at innovative prevention program
*don't cut at incentives, they work as part of the prevention ...
*secondary prevention must be thought about, it includes reinfection along with survival log with resources available

III.Training
*reinforce that new creative things do work
*think progressively, not individually when allocating funds
*forms?? behavior change forms...
*how are funders defined-make those funders responsive to the community of channel funds

IV. 10 names and numbers which have been logged in the resource data file

NOTES:

METRO TEEN AIDS 2/20/95

KEY MESSAGE:

-funding- teens can't become 50/c3
-choices as focus of AIDS ed (young people can think)
-standards of AIDS ed.
-representation on allocation boards
-fighting for credibility-
    -age discrimination
-give stats that add credibility
- teacher training
    curriculum dev. teachers and young people

WE ASK:

*Expanded federal funding for HIV/AIDS outreach education in school
*Federal policy mandating sex education as early as elementary school
*Federal policy mandating condom availability in junior and senior high schools
*Aforementioned education encompasses info inregards to HIV transmission and prevention, psyco/social ramifications of the virus, testing
*More freedom for HIV/AIDS ed. in parochial schools (if you can do anything about this)
*faculty/staff should also be better educated on HIV/AIDS

WHAT WE THINK:

*Majority of AIDS education groups are independent agencies
    -need for more gov't support and sponsorship and funding
*Transmission/preventionshould be main focus
*We need presentation techniques that will grab and keep attention of teens
*More recognition to peer educators
*Education should go before high school level student and kids
    -should be taught to jr. high kids or younger
    -face it, sex is real and happening among teens- prevention over abstinence
*More condom and general HIV/AIDS advertisements and commercials
*Less stigma upon condom distribution and availibility in schools

NAPY Conference
April 3, 1995

Wisconsin - Pam

-housing subsidies--noexistent
-Milwaukee
-NY--24 hour care with WI
-child care--none
-can say anything, no funding
-$to administrative costs
-get youth on--then enter baby talk

Miami - Raimey

-difficult speakers disclose
-physicians, etc. don't specialize in AIDS
-get $ for medical care

Columbus, OH - Neketa

-don't want to use Rev because "AIDS" is on the bill
-have to be really sick to get Social Security
-compare to cancer, leukemia
-stigma, leper

AIYSA

-military letter
-question asked "how'd you get it?"
-programs that give fill time
-evicted--access to services only if quit job previously--no food stamps, Medicaid, etc.
-need to feel busy & feel a part of
-GWM--standard of living protected
-young people told not worth investing, feeds low self-esteem
-wtting case manager training

Rafael - Latino Health (617) 350-6900*120

-no youth support services
-started support group
-AIDS Action get $, if not in Boston or don't have AIDS can't get services
-Central Consumer Service Board
    -none by youth

-usually broken down by region
-1 youth for each region
-don't use youth suggestions
-gay, bisexual, lesbian youth services

-Natural AIDS Latino Council
-cancelled
-no consumers
-purpose--prevention for

-services for HIV
-pat people on th eback who are HIV-

-home gay, lesbian, bisexual youth runaway or get thrown out, etc.

Donna Futterman

-moralism vs. realism
-can't phrase neg=condoms
-teens don't go
-providers don't believe
-stereotypes risk

-system support
-adolescent centered care
-wsts more--time, why
-1/4 076, <21 --outreach

-3 studies
-the scientific? vs. access

-adult research is more informative but pediatrics care, they just don't want to pay
-coendorsement pediatric group OK for adults, but tedious
-don't need adolescent study

Statistics

*stories - "you're too pretty"
-why still hidden
1) realistic prevention-sex positive, unequal risk
2) Broader education
3) not separate risks- all
4) adolescents explore sexuality, gay--through providers or kids

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Research

-25%
-13-19 vs. 19-24 yo transmission pattern
-emphasize HIV vs. AIDS #s
-cohort study
-parent's illusion--ideal vs reality

Lawyer -- Nancy Dubler

Adolescent development
-need to be independent vs. dep. from being sick

Trends
-lack of impact on transmission
-changes in behavior--increase in condom use, but increase social marketing prevention sector
-normalize message
-summit of youth news

Focus group
-Janet Shalwitz, Gary Remofedi, Audrey, Larry D. Angelo
-Prevention Mindy Fullilove(social contact), Mary Jane Rotham, Joyce Hunter
-Bob Johnson, Nerark Physician, ADORE
-Nancy Dubler, Abigal English
-UCSF, longitudinal adolescents at risk

NAPY GOALS & PRIORITIES

-support groups for fathers--child care
-improved health care
-NAPY provide scholarships to schools--hope for being alive
-full time student & work part time no insurance
-alternative health care
-losing HIV funding if enter substance abuse ttreatment- or diagnosed
-bring young people together (+)
-network built -newsletter -create unity
-get counseling and help deal with reality of being (+)
-define youth-different issues at different ages
-get a mission statement
-preventive health care for people who are positive
-support groups for people doing the work
-PSA on MTV-tent at Lollipalusa
-get positive messages
-easier accessibility to SSI & SSDI
-translation - cultural sensativity
-skills building - lobby set up peer support group, etc.
-create and relay structured opportunities for empowerment - TA
-get training models
-employee youth in youth programs
-fundraising

NAPY conference 3/3-6/95

Meeting with Patsy and Jeff on 3/6

Service provision:

- Counseling and testing: young people need choices. C&T should be a gateway to services
- Kicked out of foster care placement when they found out positive status. Told too young for services. Sexually assaulted and had no support, no services available.
- Resources are now going to prevention and those in stage 3. Need early intervention services.
- Housing gives a sense of security - permanency and safety. Developmental issues not considered in many welfare programs. Mental health and substance abuse don't treat young people or HIV+ well because tx is punitive. Some experience abuse in tx because they are with adults or have inept providers. Adults can't deal with young people who are positive. Administrative services are set up, but services are not provided.
- Services are needed for people who do not speak English, are blind, deaf, physically or mentally disabled, illiterate, etc.
- Alternative therapies need to be made available

Legal issues:

- The welfare system took their parents to court for money for their healthcare. They objected, one, because she's been on her own since she was 15 and didn't want to interact with her parents; and another because his parents have no money and have disowned him - "I had to hear my parents say in front of all those people that they didn't care if I dropped off the face of the earth".
- they would like greater and more real representation of their interests

Young Parent Issues:

- Stop young women from finding out they are positive when they are pregnant. They have too many tough decisions just being young and pregnant. When deciding not to take AZT because of a desire to avoid the physical and mental side effects, physician should accept the decision and not call the girl a "murderer".
- Lost her job because she was pregnant. Living on a couch, with a 3 - 4 year wait

for Section 8. No low Tcell count, so she's not qualified for SSI and there is no money for other services. Told she shouldn't have had a baby.

- Fathers need services.

Prevention:

- Young straight kids need training; they don't think they're at risk.
- Asian AIDS-ed important. Asian students beat up; "Asian invasion". If immigrants are illegal they fear deportation. Many drop out and join gangs. Look at incarcerated youth.

Debt:

- Saved up $10,000 for college, but was told he had to spend it all for medical care before he could qualify for assistance. He is now very in debt.
- Need parental consent to establish a bank account, so they risk disclosure. Can't save. Can't build for a future.
- Resigned to being in debt for the rest of their lives. They had no chance to build a savings and no chance of acquiring the earning power to pay off the huge medical bills.
- Suggestion: set up an Americorps like program so that they could do peer education in return for whatever welfare funds they are given.
- Suggestion: set up a scholarship fund so they can go to school. Make it so that other funding is not decreased in proportion to the amount of scholarship funds received.
- Once on disability can't go back to work or school. Haven't paid in much so can't get much. Asked to stop living. If get work, lose Medicaid. Asked to give up car (asset) to get a housing supplement. Donated services = income. Get money for help with rent or phone bill and was docked $80 because receiving too much income.
- Getting work without a degree is difficult

Insurance:

- Low paying jobs don't allow them to buy good insurance

- Many who work don't have insurance as a benefit
- HIV is a preexisting condition, which disqualifies them from many insurance or other reimbursements. Unfair because can be healthy for a long time before AIDS is the reason for requiring reimbursement. HIV is used as the reason for denying any reimbursement.
- Purchased insurance to pay off his car should he become disabled. He told them upfront that he was HIV+ and they still sold him the policy. Now they won't honor it.

Speaking to HIV+ youth:

- don't use "behaviors" b/c "behave" is something adults tell kids to do
- talk about risk without implying wrongdoing/ reaffirm self esteem
- talk about everyone not just gay youth or AfAm youth
- don't talk as though we are victims
- some of us don't know much about the way others became positive, eg. hemophilia or IDU language

Comments By Each Person

- Counseling and testing: young people need choices. C&T should be a gateway to services

- Young straight kids need training; they don't think they're at risk. Fathers need services. (warren)

- Stop young women from finding out they are positive when they are pregnant. They have too many tough decisions just being young and pregnant. When deciding not to take AZT because of a desire to avoid the physical and mental side effects, physician should accept the decision and not call the girl a "murderer". (lisa)

- Kicked out of foster care placement when they found out positive status. Told too young for services. Sexually assaulted and had no support, no services available. PF- multiple pieces of life need to be considered. (jody)

- Resources are now going to prevention and those in stage 3. Need early intervention services. JL-gateway to care...basic standard of care for all PWHIV+...prolong life...provide for a healthy life. (demetri)

- What is new in the RW reauthorization for youth? Define young people 13-26. JL -more language on inclusivity...decision-making...youth at the table...need training. (antigone)

- Once on disability can't go back to work or school. Haven't paid in much so can't get much. Asked to stop living. If get work, lose Medicaid. Asked to give up car (asset) to get a housing supplement. Donated services = income. Get money for help with rent or phone bill and was docked $80 because receiving too much income. (jody)

- Asian AIDS-ed important. Asian students beat up; "Asian invasion". If immigrants are illegal they fear deportation. Many drop out and join gangs. Look at incarcerated youth. (lom duc)

- Housing gives a sense of security - permanency and safety. Developmental issues not considered in many welfare programs. Mental health and substance abuse don't treat young people or HIV+ well because tx is punitive. Some experience abuse in tx because they are with adults or have inept providers. Adults can't deal with young people who are positive. Administrative services are set up, but services are not provided. (david)

- Lost her job because she was pregnant. Living on a couch, with a 3 - 4 year wait for Section 8. No low Tcell count, so she's not qualified for SSI and there is no

money for other services. Told she shouldn't have had a baby. (lisa)

- Services are needed for people who do not speak English, are blind, deaf, physically or mentally disabled, illiterate, etc. (raphael)
- Getting work without a degree is difficult (sam)
- Alternative therapies need to be made available (antigone)
- The welfare system took their parents to court for money for their healthcare. They objected, one, because she's been on her own since she was 15 and didn't want to interact with her parents; and another because his parents have no money and have disowned him - "I had to hear my parents say in front of all those people that they didn't care if I dropped off the face of the earth". (butch and lisa)
- Saved up $10,000 for college, but was told he had to spend it all for medical care before he could qualify for assistance. He is now very in debt. (butch)
- Purchased insurance to pay off his car should he become disabled. He told them upfront that he was HIV+ and they still sold him the policy. Now they won't honor it. (jody)

Donna Futterman
NAPY Conference
April 3

-Until this year no study for teens
    -impact of puberty
    -hemophilia study, adolescent did best
-Provider required
    -like young people
    -accessible services, no independent access to Medicaid transportation issues
    -confidentiality
    -consent, most can for testing, few for services
-Montefiore Program
    -city wide referrals
    -counseling and testing
    -medical care
    -psychosocial services
    -clinical research
    -training and advocacy

ACTG **C**omm**P**rog**C**lin**R**esearch**AIDS**
-study complications

Couseling and Testing
    -confidential
    -better able to link care
    -"Reality Check"
    -mandatory--prisoners, military, Job Corps
    -prob. link to care

Goals of Comprehensive Care
-psych
-disclosure
-support groups
-ongoing risk reductions
-ed. and job training
-case management, managed care concerns that force patient to go to a specified provider

Medical
-health care maintenance
-immunologic monitering
-additional medications
    -negotiate
    -choice
-O. I. Prophylaxis

-PCP can be prevented
-Bactrim
-teens lowest rates of taking
-concurrent medical problems
-clinical trials

Routine care - "Guide to Comprehensive Care for Adolescents"
-T-cell count, physical exam, TB, pap smears, Av vaccine, toxium - initially less than 200, eye care, and all systems

Living Will & Child Care

Reproductive Health
-contraception
-decision-making on pregnancy
-coordination of primary and prenatal care
-parenting skills & child care

Immunizations for Teens
-flu, yearly
-pnemon~coccal, possibly given again , baseline
-measles, mumps, rubella, -baseline
-tetanus
-hepatitus B
-hemopholus B

Symptoms
-fever greater than 103
-fever greater than 101 for 3+days
-shortness of breath
-persistent diarrhea
-unusual bleeding
-persistant headache
-localized weaknes, paralysis
-visual changes
-changes in mental status , moods out of it

Malnutrition in AIDS is multifacited
-Treatment
-identify & treat pre-exisiting
-control replication of virus
-enhance immune
-prevent 01 chemopho
-diagnose & tx 01
-CD4 count schedule

--AZT stops disease 6mo. -18mo.
--AZT decision to take, when feeling good or when start feeling bad
-combo strategies= prevent resistance
-stop virus entry at different points
-AZT, Ddl, DDC, D4T

-protease inhiibtor & 3TC both work well AZT
-MORP--Multiple Opportunistic Pathogen Prophylaxis
-Interlukin - helped Tcells go up & stay up problem- strong, feel like having flu
-flu shot

-<500 Tcells. think about AZT

National Network meeting January?

CDC report- school based
cong. stopped
compare in and out data
(Gary West)

Kids who live in suburbs attracted to street life

careful demonizing

to whom message is communicated

(Prentice)

comm color- dc range message in own language (Mike Coca)
define focus groups
self esteem
consistent message
- work with
-supportive environ
staff reflect
physical
address basic needs first
harm reduction- Edith Springer
tricky
factual message

Commission report-
Public health report- do no harm
Bring families into report
AIDS as a family issue
-explain form
-connections

Women- having kids, susceptible
prevention dollars
equality in and out of school
Show cost effective
physician- Medicaid issue- mention

Free confidential testing
parents where to go for info, how to comm

Public health- integrate message other diseases

testing not ed tool- don't combine

Rec- reports that could be

>>>>>>>>>>>>>>>>>>>>>>>>>>>>>>

-highlight what has happened and how existing avenues c used

-trends: intentional infecting (suicide, fit in) gay

-subculture- youth want to be HIV+

-need info on long term mental health issues

-lesbians getting pregnant by gay youth to prove not lesbi lesbian myth

-put in terms of someone's story

Meeting with Wayne Smith
-report worthless if no new information
(put intro)
-relapse problem
-17 yr old fe
males- little knowledge, much sexual experience
-city San Francisco bankrupt-losing AIDS money
General Hospital Ward 86-cut
-1000 AIDS deaths a year
-send questions

AIDS Policy Center Focus Group
May 2, 1995

Participants: Raquel Whiting; Chris Hall, David Harvey, Warren Nicholson, Gilbert Pickett, Jennifer Filpo, Rafael Sainz, Barbara Warren, Yvette Adams, Sam Scott, Jeannie Wong, Dawn Saucier, Bret Rudy, Art Becker, Alex Danford, Christopher Turnbull, Sean Sasser, Janet Shalwitz, Demetri Moshoyannis, Lisa Da Valle, Alexandra Milonis, Brenda Kunkel

The purpose of the meeting was to review the structure of the report and get input into both the content and the process of developing the report. Copies of the purpose, audience and perspective as well as a detailed outline of the report structure were distributed to participants for their feedback. While we have synthesized your comments according to topic, we intend that they reflect <u>your</u> voice, not ours. Please let us know if we have omitted a comment.

Your comments on the content of the report:

1. The report should be implementation oriented - recommendations are key. The recommendations should be usable and specific to people in different roles. The report is a vehicle for what works.

2. There is no permanent, institutionalized, federal-wide youth and HIV programming plan. Leadership is needed. What has been done is not enough. Special Projects of National Significance, Ryan White program, is in danger and no other program has seized the moment. CDC focuses mostly on in-school youth.

3. APC is developing a counseling policy statement, the National Alliance of Positive Youth is writing a report, and there are other existing documents that the report should complement/include.

4. Youth-centered services and youth involvement are key principles (not just p.c.) that need to be seen throughout the report. Recommendations should specifically describe how these concepts can be put into practice on a community-level and how meaningful youth involvement can take place on all levels of policy and program development and implementation.

5. The youth related successful activities and gaps in the various Ryan White titles should be described.

6. Ensure that issues for youth of color, gay/lesbian/bisexual/transgender youth, homeless youth, geographic representation, etc., are addressed in the report and that we seek out input from these groups as we develop the report.

7. Incorporate family structure issues into the discussion about youth and their environment.

8. Address the content and quality of sex education in the schools.

9. Key issues include: self esteem, health insurance, peer-based models, access to the health care system and health care information.

10. National statistics don't reflect local realities.

11. People in power need basic education and a powerful call to action. They need specific information on what is needed and how to take action.

12. Address key political issues head on. Concern was expressed over whether crucial statements would be edited out by reviewers.

Your comments on the report structure:

1. Open with a goal statement. Ideas: prevention, access, HIV health care, building self-esteem, youth involvement.

2. The AIDS 101 piece should be small or in another place and speak about youth issues.

3. Keep the purpose broad: educate, raise awareness and action. The audience may be too broad if the purpose is to get key power players to take action.

4. Do an executive summary or brochure version or develop a kit that would rephrase the key messages from the report in a way that reaches different audiences, such as young people, parents, congresspersons, community and religious groups.

5. If the audience is too broad, the report could be watered down.

Your comments on the report development process:

1. Maintain the voice of the President/ONAP since this is the strength this report has.

2. Input from the research (Adolescent Research Network) area is needed.

3. Participants offered to help in the review and writing.

4. Communicate with youth and get them involved, for example through conference calls, etc.

5. The report needs to speak to general adolescent themes as well as ensure that issues for youth of color, gay/lesbian/bisexual/transgender youth, homeless youth, geographic representation, etc., are addressed. Seek out input from these groups as we develop the report.