

GNP+NA / RMP+AN
c/o National Association of People Living With AIDS
8401 Colesville Road, Suite 750
Silver Spring, MD 20910

North America Pre-Conference Consultation & Focus Groups

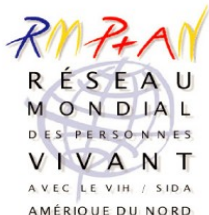
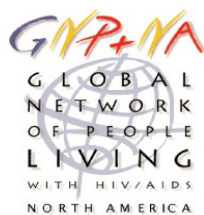


*Living 2008 –
Positive Leadership Summit*


AIDS 2008 International Conference

Mexico City

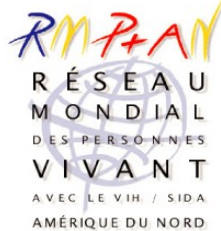
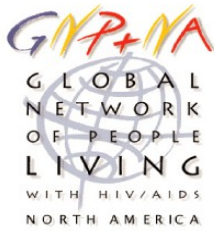




GNP+NA / RMP+AN
c/o National Association of People Living With AIDS
8401 Colesville Road, Suite 750
Silver Spring, MD 20910



Summary.....	2
Toronto Summary – March 29, 2008	5
Washington DC Report – May.11 and 16, 2008	10
Ottawa Report – June 11, 2008	14
El Paso Report – July 1, 2008.....	17
New Jersey Consultation - July 8, 2008	18
Consultation Agenda - Appendix 1	20
Project Background - Appendix 2	21



GNP+NA / RMP+AN
c/o National Association of People Living With AIDS
8401 Colesville Road, Suite 750
Silver Spring, MD 20910

Summary

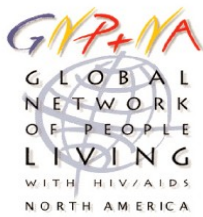
The Global Network of People living with HIV/AIDS – North America (GNP+NA) held 6 consultations/focus groups – two (2) in Canada and four (4) in the United States with approximately 250 participants in total and based on the four themes identified at the HIV+ Monaco meeting. The ultimate goal of the consultation process was to develop our knowledge, enhance our understanding, and clarify our positions on the four themes as much as possible before launching them at the LIVING 2008 Summit.

Participants commended GNP+ for undertaking this consultation process and expressed appreciation for the opportunity to share their knowledge, voice their opinions and views, and, suggest courses of actions that could be undertaken to address the issues. In gleaning the reports appended from the various local consultations, we are able to make the following observations of the commonalities and suggestions for action:

Positive Prevention: It is clear that many PLHIV are not familiar with the definition and this approach to prevention. It is felt that for Positive Prevention measures to be successful, it would require peer support, buy-in from the PLHIV community and opportunities for PLHIV involvement in the design and implementation of this initiative as well as a coordinated communication mechanism to ensure an informed and knowledgeable PLHIV community.

Criminalization: The majority of participants disclosed that their knowledge of applicable local and national laws is negligible. There was agreement on proven cases involving intentional transmission of HIV, however, they view criminalization as a violation of fundamental human, sexual, and reproductive rights and that criminalization of HIV transmission will be detrimental to good public health practices. It was suggested that GNP+ could and should play a leadership role in advocating for universal laws on criminalization as well as undertake an information and awareness campaign on this issue.

Sexual and Reproductive Health and Rights: PLHIV must have the freedom of choice regarding consensual and pleasurable sexual expression and the freedom of choice, have the fundamental right to access sexual health information and comprehensive sexual health services. PLHIV must play a vital role in the decisions that affects our own sexual and reproductive health and rights and the importance of a PLHIV participation in implementing sexual and reproductive health services.



GNP+NA / RMP+AN
c/o National Association of People Living With AIDS
8401 Colesville Road, Suite 750
Silver Spring, MD 20910

Access to Care, Treatment and Support: ACTS is more than having access to ARV's and this is only a part of a holistic approach to one's health. PLHIV need to be part of the development process that defines the medical and social standards of care and support and must include issues and concerns of vulnerable groups, immigrants and migrants, women, children and ethnic groups. PLHIV need continuous training and education programs to ensure that, as experts, PLHIV have the necessary information and background that embodies all the aspects of access to care, treatment and support. There needs to be a concerted effort to address the disparities that exist within Canadian provinces and within the member states of the US.

Acknowledgments:

GNP+NA acknowledges the hard work and dedication of its volunteer Board of Directors for their individual contributions in the development of an implementation plan for this project, acted as facilitators, provided support and orientation to those organizations who actually did the consultation, and editing and suggestions for the North America report.

GNP+NA also acknowledge the Ontario HIV Treatment Network (OHTN) who contributed \$10,000 (Canadian) in support of this consultation process.

GNP+NA appreciates this opportunity to work collaboratively with GNP+ on these important issues, for the financial support to undertake this consultation, and taking the necessary measures to ensure that our constituents had the opportunity to voice their issues and concerns for consideration at the Living 2008 Summit and beyond.

All the consultations used some or all of the following guiding questions :

Positive Prevention:

What is your understanding of Positive Prevention?

What has been your experience of Positive Prevention?

What are the pros & cons of Positive Prevention?

Criminalization:

Do you know of the current laws dealing with HIV/AIDS and criminalization?

How does this affect you or people around you?

How do you see effecting changes?

Do you think that criminalization changes sexual behaviours ?

Sexual and Reproductive Health and Rights:

How is the statement you read reflective of your situation?

What does sexual reproductive health and rights means to you?

What do you perceive your limitations and/or restrictions regarding your full sexual expression and reproductive rights?

What do you see as your role in advocating for necessary change?

Access to Care, Treatment and Support:

In your view, do you think that Canadians have adequate access to treatment, care and support?

Who do you see is responsible for providing financial resources & developing policy in addressing A.C.T.S.?

How can we play a role in advocating change?

Toronto Summary – March 29, 2008

GNP+NA held its first face-to-face focus group and consultation with approximately 85 people living with HIV through a collaborative effort with the Ontario AIDS Network as part of their annual meeting and skills building event.

Criminalization – 40 participants

Approximately 50% of the participants had little knowledge of the current laws dealing with HIV/AIDS and criminalization.

- Isolated incidences of arrest/charges for the transmission of HIV/AIDS, most of which have been sexual in nature while other modes of transmission are overlooked and unreported. Many cases are not reported and some people have settled out of court.
- The act itself is unclear and open to various interpretations. The law is not inclusive and it is not written in language that is understood by most lay persons. Law needs to be clarified.
- Ambiguity in charges being laid causes controversy.
- Not a lot of conversation on topic.
- Media sensationalizes the situation.
- Need for education and awareness of at-risk activities /myths.
- One region of the country might lay a charge of aggravated assault while another region could take the same scenario to another extreme – need for a coordinated national definition adopted by and applied through the various jurisdictions.
- Shared responsibility, responsibilities of the negative person not taken in consideration.
- Some lawyers and judges have a personal biases, pre-conceived ethical and moral positions therefore need to sensitize and educate judicial system,
- It is the responsibility of government to educate, provide training and interventions with various departments and communities.
- High risk groups – both are responsible
- Laws need to be changed – do not release names of people who are charged until proven guilty
- Often overlooking the extenuating circumstances leading to transmission
- Confidentiality factor between client / service provider and the legal obligations on the service provider.
- Need awareness and education programs of other unsafe behaviours under the Criminal Code.

Access to Care, Treatment and Support - 30 participants

- Health care in Canada has been compromised by government funding cuts.
- Not enough nutritional value.
- Compromises Health Care.
- Inadequate income levels to maintain quality of life.
- Rural issues not being addressed.
- First Nation Issues:
- Discrimination in First Nation communities not being addressed
- Lack of support to First Nations in addressing factors that contribute to the spread of HIV/AIDS, ie lack of clean drinking water, etc.
- Care and support disparities in First Nation Communities. Disparity in access to treatment and support services
- Correctional Facilities and inadequate services to those incarcerated.
- Availability and funding for alternative and/or complementary treatment options.
- Housing.
- Addictions & Drug dependency.
- Sustainability.
- All levels of government must strive for universal access and provide the leadership required at the international level to meet goals set and agreed upon.
- The needs of 10-25 years ago are not the same as they are today therefore various levels of government has to rethink the needs and to be proactive in addressing HIV/AIDS.
- PLHIV community needs to lobby government for sustainable funding streams on all the issues that impact a comprehensive response to HIV/AIDS.
- Advocate for implementation of GIPA principles in all decision-making processes, i.e. government, ASO/NGOs. Tokenism is still an issue.
- Advocate and lobby for Accountability and Transparency on all issues that impact the lives of PLHIV.
- Strategize and promote the involvement of community members.
- PLHIV need to mobilize and be proactive on issues that impact quality of life issues.
- Recognize the positive opportunities that exist while acknowledging challenges through structured feedback.
- Coordinated communication mechanisms to ensure an informed and knowledgeable national PLHIV community.
- Continuing education for health care professionals.

Positive Prevention - 45 participants

- Many participants did not know about Positive Prevention (PP).
- The Ministry of Health is working with the gay community to develop a position paper on positive prevention.
- CAS (Canadian AIDS Society) is also developing a discussion paper. Generally, there is not a good understanding of what is Positive Prevention.
- There is a need for concrete information on transmission, viral load, and criminalization.
- The focus of PP should be on people's well-being as a whole. Not HIV positive vs negative.
- We are all responsible for preventing transmission.
- PP needs to address the diverse community in Toronto so there is need for diverse prevention messages.
- Women infection rate is increasing.
- GNP+NA needs to reach out to other PLHIV; need for peer education on topics of PP.
- PP enabling people the right to speak about new infection and death.
- Positive Prevention - prevention of new infection, prevention of deaths
- Stigma still exists in Toronto – “judge putting on mask to talk to PLHIV”.
- The language around prevention needs to be inclusive and not stigmatizing
- What is the responsibility around prevention; there are different health concerns for people with HIV, re-infection, super infection, ‘serial sorting’, becoming infected with a strain of virus that is resistant to some ART.
- In the aboriginal community, the message get to them when they see others living with HIV; women are not willing to come forward; positive people need to share with others.
- Many people have not heard of the term PP
- Native women who are HIV positive are paid to leave the reserve and asked to leave the community and not buried on the reserve.
- Many people still do not know about HIV.
- PP has a good tie in with leadership; what is positive is that PLHIV must be involved in the development of PP programs.
- Is it a good prevention strategy?
- PP initiative to distribute information to people in the parks.
- There is a hidden epidemic – increasing infection rates.
- Prevention is not working – reduced funding.
- PP is equated with disclosure.
- The focus is on gay men, but statistics show that women of color are becoming infected and their concerns are not being addressed.
- Need to empower women.
- Women not involved in research and clinical trials, drugs tested on men, women deals with side effects of ART.
- Women excluded from research.
- Are straight bars doing fundraising for HIV?
- Need for more involvement from churches.

- Dispel the myth that PLHIV do not have sex.
- HIV people need to join hands to advocate for issues.
- People living with HIV need to become involved in PP policy issues.
- PP is assumed that it is relative to only gay men.
- Other voices need to be at the table.
- PP will only be successful when it is tied into education.
- We live in an AIDS bubble, outside our bubble is a society of people who have no clue on HIV/AIDS, youth think that they cannot get AIDS.
- Suburban women who are married think they cannot have AIDS.
- We need all these people to stand up and not lose their jobs, etc.
- New infections – Public Health in Ontario are expecting to get blips in new infections – the roll out of rapid testing.
- PLHIV should not be left in the dark.

Sexual and Reproductive Health and Rights – 50 participants

- The Amsterdam Statement on SRHR does not reflect clearly my rights as a PLHIV.
- Doctors are telling women not to have babies.
- It is my right to choose if I wear a condom.
- Canadians have a right to live with dignity; HIV has taken that away in this country.
- The rights of HIV+ women are being denied. Because we are women, we can not make choices. Disclosure brings rejection and mental consequences.
- The Amsterdam document reflects the ideal; not the reality.
- If you do not know where to get information, it is not readily available.
- Language and skills are barriers.
- The children that are HIV+ are totally lost with the negative messages about consequences of sex.
- HIV+ women, especially, have no confidence about their sexuality.
- The statement sounds right; but, it boils down to being accepted in the community. It comes down to who you meet in your journey in life; if you are accepted or not.
- No government has the right to prevent our human rights. They need to have programs to educate people on how to make responsible decisions and avoid transmissions; not sex or pregnancy.
- The government does nothing to protect my rights to privacy.
- You have the right to get pregnant; but, you should have the right to access to the knowledge to make decisions. Other people criminalize us and take our rights away from us.
- Medications take our reproduction rights away from us.
- We should enjoy sex, have children and make choices. Before HIV, we did not need permission. Why now!
- We can choose; but, can we live with the control and judgments of others?
- You are now able to prevent transmission to babies.
- There is lobbying for policies that restrict our rights.

- I can't enjoy sex because of the pressure from others; including other PLHIV. Disclosure issues have stopped me from enjoying this part of my life.
- I am concerned that my children are not learning from my mistakes.
- I am told by the clinic that I am crazy to think of having another child; although my three children are negative.
- We are being penalized; because, sexuality is a taboo. Governments are willing to support people that have substance use issues; they spend a lot of money on these people. However, they stigmatize and criminalize us.
- I will always disclose when I become involved with someone. If I don't disclose; you don't know me. How can we have a relationship?
- I have lost more than rights; I have lost a lot of myself. I have to deal with discrimination and others making decisions for me.
- The lack of sexual closeness has made the community unhealthy. Women carry the burden in this matter.
- If they can pass laws about our rights, they need to pass laws to punish people that discriminate against us.
- Repeal Section 22.
- The government and PLHIV need to sit together and talk.
- We need to have more dialogue between all concerned.
- We need to disseminate education and fight for our rights.
- We need to ensure that there is someone representing us at every level.
- Accept that you are not the one to blame.
- Our role is to continue to have sex, have our babies, and teach people that they can not control us.
- Teach our children healthy sexual role models.
- We need to reclaim our lives.

Washington DC Report – May 11 and 16, 2008

GNP+NA held two focus group consultations with 40 People Living with HIV/AIDS (PLHIV) in Washington DC. The participants were drawn from The DC Metro Teen Youth Group and the African Immigrant Initiative. Both groups have membership and affiliations from PLHIV and their dependants' through-out the metropolitan area covering DC, Maryland and Virginia. Facilitation and coordination was managed through a collaborative effort with Complementary Health Partners (CHP) a local consulting outfit with expertise in HIV/AIDS policy, health care and research. This exercise was an opportunity for participants to voice their opinions and issues to assist gathering evidence and opinions from PLHIV in regards to specific issues as outlined below. The consultative exercise took place on two different dates with two distinct populations i.e. May 10 and May 16 respectively. Please note that the two consultations were modeled on the Canada consultative process with noticeable changes as necessary.

Positive Prevention

This summarizes the consultation for both the DC Metro Youth and the African Immigrant Initiative (All). Majority of the participants had heard about Positive Prevention (PP) however, there were varied levels of understanding as to what it really means. Both groups noted that PP was largely known as a Center for Disease Control (CDC) and prevention concept and they had reservations in how effective and applicable it is to their respective groups. In responding to the three standing questions, the groups came up with the following summary responses:

- PP is a strategy that utilizes PLHIV to propagate HIV prevention mainly through social marketing and peer education
- PP enables CBO strengthening through GIPA
- The concept is extremely difficult to apply to the immigrant community due to several factors that include stigma and discrimination, lack of understanding of the health delivery system in the United States and lack of cultural competence by health care providers.
- Young people find peer to peer information and educational support very effective whether positive or not
- We are all responsible for preventing transmission.
- PP needs to address the diverse community in the DC metropolitan area so there is need for diverse and targeted prevention messages.
- Immigrant women are more impacted by the negative connotations of PP.
- PP is advocated for to us by service organizations but we think it should be our agenda.
- We want it changed from PP to (Prevention Efforts by PLHIV)
- There is inherent stigma.
- The CDC driven messages around prevention need to be changed and be developed by the youth positive youths themselves.

- GNP+/NA should be at the forefront and design these messages and interventions with our input
- For the immigrant community the issues that need to be addressed are clearly different from the local initiatives.
- Most immigrants who are positive are not aware of these terms.
- GNP+ should outline issues around unintended disclosure of status and put together a counseling protocol for those who get caught up in forced or unprepared disclosure of their status and still do not know how to handle the obsequies.
- PLHIV want GNP+/NA to be their safety need and they want GNP+NA to consult and work with its constituencies and not wait to be given prescriptions by big organizations.
- PP need to be cognizant of the affected children of PLHIV and their views need to be considered and heard
- Other voices need to be at the table
- PP is more likely to perpetuate stigma and discrimination if done in the current format which is CDC based.
- Women and children's voices are rarely heard.
- On the surface it provides for an opportunity for us to contribute to both prevention and enhancement of livelihood for PLHIV.

Criminalization

Approximately 98% of the participants were not familiar with the current laws dealing with HIV/AIDS and criminalization.

- GNP+ should work with the legislature and the judiciary to impress upon them that that criminalization itself undermines prevention efforts
- The courts should move up with the times and scientific understanding of HIV prevention and transmission.
- Criminal intent should be established beyond doubt in any litigation
- Social behavior should be well understood by the judiciary, they should not merely convict a PLHIV for not disclosing their status. They have to weigh the circumstances of how the parties met and whether or not they are both culpable of engaging in risky behavior then determine the proportional merits of each of the parties' actions
- Willful transmissions is differentially legislated by each of the states and the federal government/congress should come up with a standard process that results from consulting PLHIV.
- Ambiguity in charges being laid causes controversy.

Sexual and Reproductive Health and Rights

The participants noted that the applicability of these rights vary by population, age and gender.

- Immigrant women felt like adopting these rights was a violation of their cultural norms and standards and that may lead them to estrangement with their own people.
- Negotiating and communicating sex and family planning should be a prerogative of individual families and standards should only serve as guidelines.
- Rights come with responsibilities and we should accept both.
- The Paris declaration of 1994 bestows the right to marry and found a family on PLHIV and with drugs now available PLHIV should not be restricted or talked into not having children.
- Family expectations and cultural practices impinge on sexual and reproductive rights.
- In-laws expect babies otherwise they will want to know why there are no babies
- Babies rights are also now protected but GNP need to advocate for pediatric ARVs and standardization of such medicines.
- With the advent of drugs and medical transformations PLHIV should be having babies if and when they choose without prejudice.
- PLHIV have an inherent responsibility to disclose their status but their partners have an equal responsibility to protect themselves at all times as well regardless of disclosure.
- GNP+/NA should take the lead by having more consultations with PLHIV and then take our issues up at policy level.
- We ready to share our thoughts and declare our rights.
- We can only represent ourselves and therefore the mandate of GNP+ should never be to do anything else other than representing our interests at any and all forums.
- Parents have a responsibility to share with children so that these kids grow up knowing and understanding the consequences of being affected or infected.
- As Youth, we have an opportunity to produce a new generation free from HIV.

Access to Care, Treatment, and Support

- As immigrants, we do not understand the American health care system.
- It's expensive, disorganized and that is shameful for such a rich nation.
- American health care system was never designed for immigrants and therefore we need CBOs that cater for the interest of immigrants and PLHIV in particular.
- Even though the region is blessed to have clinics like Whitman Walker, the stark differences in culture and customary norms forces immigrants to shy away from such providers because they predominantly serve the gay community.
- Coming into a new country has so many challenges including health and nutrition and we are beginning to see new eating and disease patterns that are otherwise uncommon to Africans.
- We need youth friendly services at all health centers.

- Other than the children's hospital, there are no service providers that dedicate services for PLHIV youth.
- GNP+ needs to be re-examined and include young people on the board.
- We need youth voices at all levels.
- GNP has not lived up to its expected role as the organization that represents PLHIV.
- We need GNP+ to speak up through and for us
- We want to help strengthen GNP+ become a strong voice that identifies with its constituency.
- We want governments and other agencies to recognize, respect and even be fearful of GNP+.
- We are bigger than the United Nations body and yet our voice is so hollow and shrill. We need to revamp GNP+ so that we are heard and we sit at the table.
- Mexico City should a watershed conference and should unveil a new rejuvenated GNP+ with a clear and transparent agenda.
- We should reclaim GIPA back and make it our agenda again.

Ottawa Report – June 11, 2008

GNP+NA held its second Canadian face-to-face focus group/consultation with approximately 52 people living with HIV/AIDS as a pre-Forum event to the Canadian AIDS Society's Annual PLHIV Forum and AGM on June 11, 2008.

Criminalization:

Approximately 40% of the participants were not familiar with the current laws dealing with HIV/AIDS and criminalization.

- Lack of education, knowledge and awareness available.
- Empower PLHIVs
- No input in developing policy and laws.
- Increase in infections – denial of status.
- Sexual vs other means of transmission.
- We need to be analytic in our approach.
- Ignorant and biased judiciaries.
- Apathy in PWHIV community.
- Criminalization is discriminatory to PLHIVs, not just the intentional transmission.
- Some groups are working on the issue.
- Long-term goal is to effect change, law is evolving and we need to recognize the realities.
- Purpose of law is more of a question of prevention to stop the epidemic.
- Every situation is unique.
- It is a violation of human rights.
- Use evidence-based data to inform the decisions.
- Guilty till proven innocent.
- GNP+ could play a leadership role in advocating for universal laws on criminalization.
- There are no parameters set around disclosure.
- Disclosing vs confidentiality.

Access to Care, Treatment, and Support (ACTS)

- Many of the issues challenging ACTS are not being addressed.
- Disparities for ACTS in various affected populations.
- Holistic and inclusive services are lacking by underfunding.
- There are gaps and disparities to ACTS both at the federal and provincial levels.
- There is endorsement for universal access but there is no apparent solidarity in pushing the agenda forward.
- Socio-economic issues, ie poverty, etc.

- Lipodystrophy and organ transplant are issues not receiving the attention required to address the challenges.
- Availability and funding for alternative and/or complementary therapies options.
- Housing
- Addictions & Drug dependency
- Sustainability
- Identify barriers and create framework to address universal ACTS.
- Using and sharing model for best practice and standards of care.
- Decision-makers need a reality check as they are not aware of all the issues yet to be addressed.
- PLHIV must advocate from evidence-based and anecdotal data.
- Maximum Assistance Therapy.
- There is no political will at the federal and provincial levels for entering into collaborations.
- Need to move to reciprocal accountability and evaluation of outcomes.
- Addressing Aboriginal issues that include: stigma and discrimination, poverty, and factors that contribute to the spread of HIV/AIDS, ie lack of clean drinking water, etc.
- Correctional Facilities and inadequate services for those incarcerated.
- Coordinated communication mechanisms to ensure an informed and knowledgeable national PLHIV community.
- Renewed awareness and education campaigns targeted to health care professionals.

Positive Prevention

- Many of the participants were unclear on the definition and purpose of Positive Prevention.
- It was reiterated the federal government Department of Health is working with the gay community to develop a paper on positive position and that CAS (Canadian AIDS Society) is also developing a discussion paper.
- Factual information on transmission, viral load, and
- Fear that PP will jeopardize PLHIV safety and security and lead to criminalization.
- Not HIV positive versus negative.
- We are all responsible for preventing transmission.
- PP needs to address the diverse communities and requires diverse prevention messages.
- GNP+NA needs to reach out to other PLHIV; need for peer education on topics of PP.
- Positive Prevention = prevention of new infection, prevention of deaths
- Stigma and discrimination continues to create barriers and challenges.
- Clear language around prevention needs to be inclusive and not stigmatizing
- What is the responsibility around prevention; there are different health concerns for people with HIV, re-infection, super infection, 'serial sorting', becoming infected with a strain of virus that is resistant to some ART.
- Many people have not heard of the concept and the term PP
- PP has a good tie in with leadership however, PLHIV must be involved in the development of PP programs.
- Is it a good prevention strategy?
- PP is equated with disclosure.
- Need to empower women.

-
- Need for more involvement from churches.
 - Work to disclaim the notion that PLHIV do not have sex.
 - HIV people need to join hands to advocate for issues.
 - PLHIV need to become involved in PP policy issues.
 - PP is a responsibility of all PLHIV and not only gay men.
 - Other voices need to be at the table.
 - PP will only be successful when it is tied into education.

Sexual and Reproductive Health and Rights

- The Amsterdam Statement is idealistic and does not emphasize the rights of PLHIV.
- Healthcare providers need to be more aware and education of SRH.
- General information on SRHR is not readily available.
- Language and skills are barriers.
- HIV+ Youth are confused and need with the negative messages about consequences of sex.
- HIV+ women, especially, have no confidence about their sexuality.
- The statement sounds right; but, it boils down to being accepted in the community. It comes down to who you meet in your journey in live; if you are accepted or not.
- We need to have programs to educate people on how to make responsible decisions and avoid transmissions.
- The government does nothing to protect my rights to privacy.
- You have the right to get pregnant; but, you should have the right to access to the knowledge to make decisions.
- Other people criminalize us and take our rights away from us.
- Medications take our reproduction rights away from us.
- We should enjoy sex, have children and make choices. Before HIV, we did not need permission. Why now!
- We can choose; but, can we live with the control and judgments of others?
- Laws and policies that restrict our rights.
- I can't enjoy sex because of the pressure from others; including other PLHIV. Disclosure issues have stopped me from enjoying this part of my life.
- Feels like I am being penalized and made to feel guilty about sex and entering into a relationship.
- We deal with stigma and discrimination and others making decisions for us.
- Decision-makers and PLHIV need to dialogue.
- We need to disseminate education and fight for our rights.
- We need to ensure that there is someone representing us at every level.

El Paso Report – July 1, 2008

PLHIV Pre-Consultation conducted July 1, 2008 on the United States-Mexico border in El Paso, Texas. There were 32 HIV Positive individuals present

Access To Treatment, Care & Support

- PLHIV need CONSISTANT access to HIV medications!
- PLHIV should have a stronger voice and be heard by the government.
- Funding for critical support services have been cut. PLHIV need such services as support groups, case managers, food, transportation, and psychologists.
- PLHIV need better access to dental care.
- Agencies serving PLHIV need better communication and coordination of services.
- Peer support is critical and needs to be part of any service system.
- There needs to be a stability of case managers / counselors. They need to be better trained and more knowledgeable.
- PLHIV encounter roadblocks from agencies in receiving services and are often passed around from agency to agency.
- PLHIV ask to be treated with respect.

Positive Prevention

- PLHIV need access to secondary prevention including treatment information, education, and adherence counseling.
- Peers need to be involved in all aspects of education and prevention.
- PLHIV need programs that discuss sex openly, honestly and graphically. This should be inclusive of both straight and gay individuals.
- There should be more honest discussions of unprotected sex, alcoholism and drugs.
- Celibacy should be respected as a decision for PLHIV.

Criminalization

- Criminalization is counter productive to stopping the spread of HIV.
- Criminalization does not acknowledge the responsibility of the uninfected partner.
- Disclosure of status is not always necessary if risky sex is not involved.
- Criminalization laws are homophobic and sex phobic.
- Criminalization punishes many PLHIV's, creating fear discrimination and stigma.

Sexual and Reproductive Health and Rights

- PLHIV have the right to have sex.
- PLHIV have the right to have children.
- Primary prevention for HIV negative individuals should include information on having safe relations with HIV positive individuals.
- Risk Reduction and Health Education must return to prevention programs funded by governments.

New Jersey Consultation - July 8, 2008

The New Jersey Women and AIDS Network conducted a focus group discussion with sixteen women at the Broadway House for Continuing Care in Newark, New Jersey on July 8th. The average age of the women was 47 years old. Most women were HIV infected for more than 12 years. Most were on antiretroviral medications. Most participants were heterosexuals and some used contraceptives. They all had children. Most were open about their HIV status, but three said they were not. Most have disclosed their status to family, friends, and others. The participants responded to the same questions as other consultations. The women welcomed the opportunity to discuss these issues that were relevant to HIV positive people. A summary of the responses are listed as follows:

Positive Prevention

- Most participants defined positive prevention as their individual responsibility not to pass on HIV infection.
- “It means that you are HIV positive and you do not want to pass it on to someone else”
- “You gotta prevent yourself from passing it.”
- “Do whatever necessary to stop transmitting!”
- Using universal protection, i.e. latex condom and gloves.
- They spoke of wanting to learn more about HIV, i.e. HIV basics/HIV 101.
- Taking care of oneself was important in not transmitting HIV.
- “not having sex”
- “Not ashamed to say, I don’t know as much as I should.... Need to learn more”
- Some admitted not knowing a lot about the disease and how it is transmitted.
- They said they needed more support and education around positive prevention, i.e. support groups, family support, newsletters, etc.
- They saw their role as educating the larger population on prevention, “A lot of us are capable”.
- Some spoke of their own naivety on HIV disease.
- They acknowledged that HIV “does not have to be a death sentence”.

Sexual and Reproductive Health and Rights

- Participants spoke of their personal experiences, i.e. some spoke of being raped.
- Some spoke of mental abuse.
- They said that everyone has a role and can control who they have sex with.
- They have a choice and a fundamental right to educate themselves.
- “You have to be honest and take care of yourself”.
- They spoke of building self esteem – “Care about you first”.
- They shared on starting new relationships, “I have everything I need to protect myself from him and everything he needs to protect him from me”
- Some abstained from sex, “Not worried about sex anymore.”

- They still had sexual desires, and that they wanted affection and intimacy.
- Some said in their quest for intimacy, because of their desires; sometimes they forget about standards.
- “You are ashamed and believe you don’t deserve much”.
- They spoke of their fear of disclosure, because they do not want to be rejected.
- Some stated that “rejection doesn’t hurt anymore”.
- Some people put you in a box and people do not see you as a person anymore.
- Very hard dealing with acceptance.
- They limited their choices, “You feel as though someone with HIV would be easier to have sexual relations with because both people are infected”.
- They spoke of low self esteem.
- Despite their fear of disclosure and rejection, they are honest about their status, “let them know who you are.”
- Learning more about HIV as well as educating others
- Let them know who you are and be comfortable within yourself
- “Today I have no shame saying I am HIV positive.”

Access to Care, Treatment and Support

- They feel that they had access to care, treatment and support. They listed the agencies from which they received services.
- They see the federal, state and local governments as being responsible for providing financial resources and developing policies in addressing access to care, treatment and support.
- They spoke of their role in advocating for change:
- Talk to youth about HIV
- Go to grammar schools (start educating the young)
- Get people who are infected on the community, planning, and agency boards to make decisions
- Investigate how public health treats women who are infected
- Provide peer support in groups

Criminalization

- They spoke of the stories they have heard in the news about people who were sent to jail because they infected other people.
- They know that if you know someone infected you and you can prove it, you can put them in jail.
- They did not know that HIV visitors and immigrant were barred from entering the US.
- They wanted more information on the HIV laws. “I don’t know the laws”.
- Newsletters should be developed that provide information on the laws.

All of the consultations were based on the following components.

AGENDA

PLWHIV/AIDS Consultation

Introduction and Presentations

- Introduce Consultation facilitators
- Presentation on GNP+ and GNP+NA
- Presentation on the e-consultation process

Session # 1

- Positive Prevention
- Criminalization

Break

Session # 2

- Right to Sexual and Reproductive Health
- Access to Care, Treatment, and Support

Plenary Session – Overview and thank you.

The Living 2008 - Positive Leadership Summit and the XVII International AIDS Conference AIDS 2008

The themes of LIVING 2008 and AIDS 2008 are closely interlinked. Especially around access to treatment, care and prevention, as well as HIV-related stigma and discrimination, the two conferences are complementary. While AIDS 2008 is being convened around three main programs - science, leadership and community - LIVING 2008 will link in specifically with the leadership and community tracks, both of which have a focus on PLHIV.

LIVING 2008: The Positive Leadership Summit will prepare people living with HIV to be not just attendees of AIDS 2008, but also leaders on the issues of importance to people living with HIV, and to work in partnership with other AIDS 2008 delegates, both HIV-positive and HIV-negative.

The LIVING 2008 delegates will lead with a unique and current perspective on treatment, care and prevention issues within AIDS 2008 through plenary presentations, abstract driven sessions, organizing satellite meetings, and conducting skills building workshops. People living with HIV, many of whom experience stigma and discrimination, human rights violations and gender inequality will lead the discussions and debates on the elimination of HIV-related stigma and discrimination. The outcomes of LIVING 2008 will be presented at a large plenary satellite at the start of AIDS 2008.

Links between LIVING 2008 and other key HIV meetings

Prior to LIVING 2008, two international preparatory meetings of people living with HIV have been organized. The Global Consultation on Sexual and Reproductive Health Rights was held in Amsterdam in December 2007. The main focus of this consultation was the development of a guidance package on sexual and reproductive health rights to be utilized in LIVING 2008. The Consultation was attended by almost 80 people living with HIV from all over the world, who together produced the Amsterdam Statement. The second international meeting was HIV+ Monaco, which Her Serene Highness Princess Stephanie of Monaco hosted on January 24 & 25, 2008. HIV+ Monaco provided an important opportunity for key PLHIV organizers to undertake preparations for LIVING 2008, including finalizing format, content, facilitators, and speakers. HIV+ Monaco provided a unique and innovative opportunity for the PLHIV movement to reflect on how it can improve knowledge and information exchange, as well as improve the collaboration among groups of people living with HIV at country, regional and global levels. HIV+ Monaco was followed by a pre-consultation with people living with HIV to further develop content and gather evidence of best practice and lessons learnt for discussion at LIVING 2008.

LIVING 2008 will strengthen the PLHIV movement through promoting the involvement and leadership of people living with HIV in the global HIV response, as well as benefiting participants and programming at both the Positive Leadership Summit and AIDS 2008.

The objectives of the Positive Leadership Summit are:

1. To identify and discuss current key issues for the PLHIV movement, including:
 - Universal access to HIV treatment, care and prevention programs;
 - Prevention, with a focus on positive prevention;
 - Sexual and reproductive health and rights of people living with HIV;
 - Criminalization of the transmission of HIV;
 - Cross cutting issues include women and most at-risk groups.

Overarching issues include addressing gender inequality, increasing involvement of young people living with HIV; stigma and discrimination; the greater involvement of people living with HIV (GIPA); and creating effective partnerships.

2. To caucus and develop common positions and strategies on key priorities to take forward into AIDS 2008 and assist people living with HIV to prepare for AIDS 2008.
3. To develop technical and leadership skills in people living with HIV as part of the ongoing effort to strengthen the PLHIV movement's ability to contribute to the AIDS response in countries.
4. To ensure the issues, outputs and decisions identified during the conference that require attention and action are recorded and followed-up in a timely manner by the Living with HIV Partnership, and especially the international networks of people living with HIV.