



**Opportunities and Mechanisms
for Involving People Living with HIV/AIDS
in the National HIV/AIDS Strategy's Implementation**

A briefing paper written by the U.S. People Living with HIV Caucus

Staffed by
Vanessa Johnson, JD, National Association of People with AIDS and
Anna Forbes, MSS, Consultant

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US PLHIV CAUCUS

United States People Living with HIV Caucus

Description

The US PLHIV Caucus is a group of organizations, coalitions, networks, client groups, and individuals who principally advocate for people with HIV in the U.S. Organizational members of the Caucus have board majorities and leadership comprised primarily of people living with HIV.

Charge

By organizing ourselves as a Caucus, we have a greater opportunity to:

1. *National HIV/AIDS Strategy (NHAS)*: Provide leadership and consultation to federal government regarding its NHAS Federal Implementation Plan. This activity will take the form of annual consultations between PLHIV Caucus and the Office of National AIDS Policy (ONAP) on national HIV/AIDS issues and any related/tangential issues, e.g. Affordable Care Act implementation.
2. *HIV Service Implementation*: Provide leadership and consultation to federal advisory and decision-making bodies, particularly with regard to "Prevention for Positives" campaigns and other program designs.
3. *2012 International AIDS Conference*: Serve as the organizing body for the US efforts to assist and support LIVING 2012 by 1) coordinating our input with the Global Network of People with HIV (GNP+) and the Conference Coordinating Committee of the IAS to assure that the perspectives and priorities of HIV positive people living in the host country are appropriately incorporated into all conference planning; 2) having a unified voice as we participate in planning pre-conference and conference sessions specifically for positive conference attendees; and, 3) serving as a welcoming body for other PLWH/A organizations and individuals attending IAS.

U.S. PLHIV Caucus Membership List (in formation)

- 20/20 Leading Women's Society
- Campaign to End AIDS (C2EA)
- Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, People Living with HIV/AIDS Caucus
- Global Network of People Living with HIV/AIDS – North America (GNP+ NA)
- International Community of Women Living with HIV/AIDS – North America (ICW-NA)
- Michigan Positive Action Coalition (MIPOZ)
- National Association of People with AIDS (NAPWA)
- Ohio AIDS Coalition
- Positive Iowans Taking Charge (PITCH)
- Positive Leaders Uplifting Sisters (PLUS)
- U.S. Positive Women's Network

EXECUTIVE SUMMARY

The rationale for involving people living with HIV (PLHIV) in all levels of governmental HIV/AIDS policy-making was first articulated in the Denver Principles published in the U.S. in 1983 and was reiterated in 1996, when it was endorsed by UNAIDS and labelled as GIPA, for the Greater Involvement of People with AIDS.

The National HIV AIDS Strategy (NHAS) issued by the U.S. Office of National AIDS Policy in 2010 explicitly articulated its commitment to the meaningful involvement of PLHIV. This commitment provides PLHIV in the U.S. with an opening to decide what mechanisms can best achieve their full inclusion in NHAS implementation and how to use our political leverage to assure implementation of those mechanisms at the federal, state and local levels.

This paper reviews the possible levels of PLHIV involvement in implementation of all aspects of the NHAS, as well as the utility and potential impact of various mechanisms for achieving it. The basic options discussed here include:

1. Require on-going PLHIV representation on decision-making bodies (e.g. Ryan White Planning Councils, Community Prevention Planning Groups, boards of publicly funded agencies, internal consumer advisory groups within agencies, and external Community Advisory Boards at the national, regional and statewide levels)
2. Consultations involving PLHIVs (solely or as one among multiple constituencies).
3. Innovative feedback mechanisms to assess services, policy implementation, etc.
4. Hire PLHIV to assure our adequate representation in policy-making and in the planning, delivery, and evaluation of HIV/AIDS services
5. Require all publicly funded HIV/AIDS service providers to supply evidence (using standardized indicators) of their effective use of GIPA mainstreaming practices as a condition of their funding.

It also discusses some of the challenges raised by each mechanism and potential strategies for addressing these challenges.

Finally, it explores the pragmatic value of the substantial investment that is essential to building the capacity of a cross-section of PLHIV organizations and individuals to participate meaningfully in the mechanisms described above. The Collaborative Fund for HIV Treatment Preparedness makes a convincing case for its position that the investment needed to help people become well-informed, effective advocates (which is the goal of authentic PLHIV involvement) is *the same investment* as that required to prepare us to use treatment effectively to safeguard our own health and, secondarily, to prevent HIV transmission.

People living with HIV commit to treatment and prevention fully only when those in government commit to involving and engaging with us authentically. Thus PLHIV involvement is, in fact, the key to stopping HIV.

INTRODUCTION

The rationale for involving people living with HIV/AIDS (PLHIV) in all levels of governmental HIV/AIDS policy-making has been globally affirmed and perhaps was most succinctly summarized by the Policy Project as a practice that promotes:

- “a reduction in stigma and discrimination associated with HIV/AIDS;
- increased effectiveness of policy and programs;
- and improvements in the lives of PLHA.”¹

The rationale was first articulated in 1983 by Americans living with HIV/AIDS who published the Denver Principles. It was reiterated in 1996 at a UNAIDS-sponsored meeting of PLHIVs in Paris where the concept acquired the acronym GIPA, for Greater Involvement of People with AIDS. UNAIDS has been promoting these principles since then. In this document, we embrace both the Denver Principles and GIPA as guideposts which help us pave the way to greater and meaningful involvement of PLHIV in the U.S.

The Global Network of People living with HIV (GNP+) noted in 2010 that, “people living with HIV are transforming their individual realities into global policy dialogue. Their diverse voices and experiences are gathered systematically using different methodologies and consolidated into recommendations for advocacy. This approach not only facilitates the development of credible, acceptable and effective [WHO] guidelines, it also enhances ownership of the process, enables people living with HIV to hold their governments accountable and forms the basis for sustained advocacy.”²

In the U.S., the National HIV AIDS Strategy (NHAS) explicitly articulated its commitment to the principles of PLHIV empowerment in stating that, “[p]eople living with HIV have unique experiences that should be valued and relied upon as a critical source of input in setting policy”³ and “[g]overnments and other institutions... should work with people with AIDS coalitions, HIV services organizations, and other institutions to actively promote public leadership by people living with HIV.”⁴ The NHAS Implementation Plan notes that “HRSA, CDC, and HHS OS will develop recommendations for strengthening the parity, inclusion, and meaningful representation of people living with HIV on planning and priority-setting bodies.”⁵

¹ Policy Project. Moving forward: Operationalising Gipa in Vietnam. Final Study Report. October 2003. Available at http://www.policyproject.com/pubs/countryreports/VIE_FinalGIPA.pdf

² Mallouris C, Caswell G, and EJBernard. How consultations by people living with HIV drive change and shape policies, programs and normative guidelines. Global Health Governance 2010. 4;1. Available at <http://ghgj.org/Mallouris4.1.htm>

³ The Office of National AIDS Policy. The National HIV/AIDS Strategy for the United States. July 2010. page 57. Available at www.WhiteHouse.gov/ONAP.

⁴ The Office of National AIDS Policy. The National HIV/AIDS Strategy for the United States. July 2010. page 49. Available at www.WhiteHouse.gov/ONAP.

⁵ The Office of National AIDS Policy. The National HIV/AIDS Strategy Federal Implementation Plan. July 2010. page 25. Available at www.WhiteHouse.gov/ONAP.

These commitments provide PLHIV in the U.S. with the opportunity to determine, for ourselves, what mechanisms can best achieve full inclusion in implementation of the NHAS and what role we will play, as a collective political force, to bring about implementation of those mechanisms at the federal, state and local levels. While some mechanisms already exist, the promise of the NHAS can be leveraged to expand and improve on them. This is also the time to review mechanisms not currently in use in the U.S. and call for pilot testing of them here, as well as to insist on effective standards for monitoring and evaluating the implementation of PLHIV involvement mechanisms by all publicly funded HIV/AIDS program implementors.

This paper will focus on mechanisms for the direct involvement of PLHIV in the local, state and federal decision-making that shapes implementation of the NHAS. It will explore the status of our current involvement in decision-making undertaken by publicly funded entities (governmental and non-governmental) and how this could be expanded and improved. While recognizing the crucial importance of other areas of involvement identified above (including advocacy, shaping public opinion, and personal involvement in treatment), the purpose of this paper is to lay a foundation for negotiating a stronger and more pervasive role in the NHAS implementation activities undertaken by publicly-funded entities, including government agencies and the various service providers with which they sub-contract.

MECHANISMS FOR INVOLVING PLHIV

A policy brief published by UNAIDS in 2007 describes areas of PLHIV involvement as shown below, ranging broadly from the personal and community level to national and international policy making levels.⁶

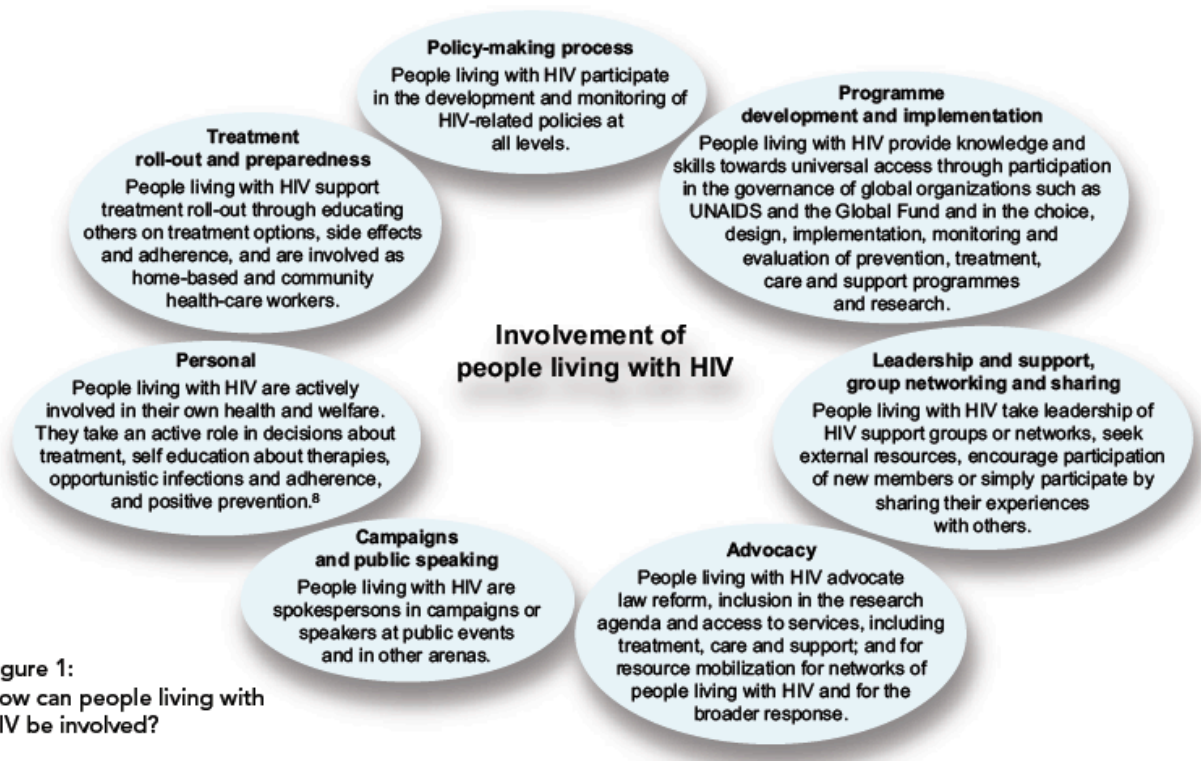


Figure 1:
How can people living with HIV be involved?

Some basic mechanisms for ensuring PLHIV involvement in policy-making include the following:

1. Require on-going PLHIV representation on decision-making bodies (e.g. Ryan White Planning Councils, Community Prevention Planning Groups, boards of publicly funded agencies, internal consumer advisory groups within agencies, and external Community Advisory Boards at the regional and statewide levels)
2. Convene consultations involving PLHIVs (solely or as one among multiple constituencies).
3. Create innovative feedback mechanisms to assess services, policy implementation, etc.
4. Hire PLHIV to assure our adequate representation in policy-making and in the planning, delivery, and evaluation of HIV/AIDS services

⁶ UNAIDS, Greater Involvement of People Living with HIV (GIPA). Policy Brief. 2007. Page 2. Available at http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

5. Require all publicly funded HIV/AIDS service providers to supply evidence (using standardized indicators) of their effective use of GIPA mainstreaming practices as a condition of their funding.

These approaches are presented below in summary format in the table below and are then extensively discussed throughout the remainder of the paper. This discussion includes strengths of each approach, inherent challenges, and potential strategies for addressing these challenges.

Table: Summary of Available Involvement Mechanisms

| Type of Mechanism | Challenges | Pre-requisites for Success |
|---|---|--|
| 1. Representatives on Decision-Making Bodies | Not enough PLHIV from all constituencies with the experience/background to participate effectively | Substantial investment in capacity-building among a cross-section of PLHIV constituencies to assure viable pool of candidates |
| | Uncertainty on policy-making bodies about what constitutes adequate representation, who does what, etc. | Clear requirements from funders re: composition, participants’ TORs, fair decision-making protocols, etc. |
| | Lack of resources, especially for PLHIV organizations, to train and support the full participation of members as well as money to compensation and reimbursement of expenses associated with travel to meetings and time taken away income-generating activities. | Substantial government investment of financial resources and technical assistance to support network membership education and development of consensus around issues, so that their elected reps. then can represent the network effectively and knowledgeably |
| | Decision-making may become resistant to PLHIV participation, scrimp on investment, and obscure their failure to meet GIPA goals | Monitoring decision-making bodies to assure transparency re: meeting representation requirements and appropriate, consistent investment in PLHIV participation |
| | PLHIV representatives may feel isolated , outnumbered and unheard by other Planning Body membership | Form PLHIV Caucuses within decision-making bodies for mutual strategy-development, support, and negotiating power |
| | PLHIV representatives, may, in fact, be out-voted on some issues | Establish “sign-off” procedures so that solutions that meet PLHIV approval must be developed on specific, highly-sensitive decisions |
| 2. PLHIV Consultations | Allow for input but give PLHIV no control over final decisions | Must be recognized as valuable opportunities for input -- but no more than that |
| | “One-off” process does not allow for discussion to evolve over time and | Outcomes should be published in report after participants have had |

| | | |
|---|---|---|
| | for new ideas to emerge and be considered | chance to review and correct draft copy – so that the record discussion is accurate and publicly available |
| 3. Feedback Mechanisms | Report Card and Indices collect valuable feedback but no PLHIV control over how/whether it is used | Governments and/or other funders can invest in the creation of tools for objective feedback collection and report publicly and regularly on their findings |
| | Feedback loops may capture evaluative information that would otherwise go unheard but this information may not affect service provision, program planning or policy decisions | Governments can require grantees and their own agencies to fund and maintain feedback loops and show evidence of their use of the data produced |
| 4. Hire PLHIV to assure our adequate representations | Resistance by other employees to working with PLHIVs and/or perceptions that PLHIV employees have unfair advantages in hiring and/or performance evaluations | Publicly funded employers educate staff, assert responsibility for countering stigma, and hire/manage appropriately so that employees perform successfully |
| | | Explore the legal implications of determining that first-hand knowledge of HIV may be a legitimate area of expertise that warrants the preferential hiring of PLHIV for some positions or as some percentage of the staff in publicly funded agencies and/or policy-making entities |
| 5. Make evidence of GIPA mainstreaming a condition of funding for government entities and grantees | When this is a “recommended” practice – but either undefined or unmonitored -- adherence to it will vary widely among grantees | Clear metrics for implementation must be in place and closely monitored to assure meaningful adherence. Assess grantees’ baseline levels with the Empowerment Index ⁷ , or another objective instrument, and use that same instrument to measure future progress . |

⁷ Strub S. “Denver Principles Empowerment Index”. 2011. Available at http://www.poz.com/pdfs/sos_empowerment_index_2011_07.pdf.

Discussion of Available GIPA Mechanisms

Mechanism 1

Require on-going PLHIV representation on decision-making bodies (e.g. Ryan White Planning Councils, Community Prevention Planning Groups, boards of publicly funded agencies, internal consumer advisory groups within agencies, and external Community Advisory Boards at the regional and statewide levels)

Since the 1990s, PLHIV representation has been required in the U.S. on Ryan White Care Act (RWCA) Planning Councils, CDC-funded HIV Prevention Community Planning Groups, in the President's Advisory Council on HIV/AIDS, etc. Most AIDS Service Organizations (ASOs) stipulate in their by-laws that some of their board or steering committee seats will be filled by PLHIVs.

Internationally, all countries receiving funding from the Global Fund to Fight HIV, Tuberculosis and Malaria convene planning bodies that develop the grant applications and national plans for use of these fund and monitor their implementations. These planning bodies, called Country Coordinating Mechanisms (CCM), are required to include representation from government agencies, NGOs, FBOs, individual experts and a required number of seats for "people living with and/or affected by the diseases".⁸

This approach has advantages and disadvantages, many of which have been identified in *Challenging, Changing, and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms*. This document presents guidelines that, "have been drawn up and agreed on by a large group of PLHIV who have first-hand experience of the challenges and obstacles to PLHIV involvement on CCMs, thus giving the guidelines value, legitimacy, and credibility."⁹ The following is an abbreviated summary of the document's key recommendations:

Re: group composition and training

- PLHIVs should make up at least 10 percent of group's membership.
- PLHIV CCM members should have alternates to replace them when they are absent.
- PLHIV CCM members should be advised re: when and where meetings are taking place well in advance of the date, so they can ensure their attendance and/or that of alternates.
- All CCM members, including alternates, should be paid travel costs and per diems where appropriate. All CCM members should receive HIV orientation and awareness training, including discussion of the GIPA Principle.

⁸ Global Fund to Fight HIV, Tuberculosis, and Malaria. Proposal Form – Round 10 Single Country Applicant. Available at <http://www.theglobalfund.org/en/searchresults/?searchtext=Clarification+CCM+requirements>

⁹ The Global Network of People Living with HIV. *Challenging, Changing, and Mobilizing: Guide to PLHIV Involvement in Country Coordinating Mechanisms*. 2005. Page 68. Available at <http://www.gnplplus.net/cms-downloads/files/handbook-EN.pdf>

- CCMs should support PLHIV in acquiring the relevant skills and capacity they require to fully participate on the CCM.

Re: network involvement with their representatives

- Terms of Reference (ToR) should be established for PLHIV CCM members and alternates by their constituencies.
- The process for selecting PLHIV to sit on CCMs should be agreed on and conducted by national PLHIV networks, ensuring inclusion of all groups and *should be totally independent of the CCM.* (emphasis added)
- CCMs should support PLHIV networks to hold meetings for discussion of CCM issues if such meetings are not already taking place.
- Every decision scheduled to be taken by a CCM needs prior discussion by the network of PLHIV. The primary position and back-up positions that network representatives will take should be agreed within the network in advance. Every decision should be made with group consultation to reflect a credible and united PLHIV perspective.
- PLHIV networks should develop partnerships with international and national NGOs, and regional and international PLHIV networks (such as the ICW and GNP+) to improve their access to technical support and increase collaboration, thus ensuring local input into global advocacy efforts.
- PLHIV CCM members should ensure that PLHIV issues are given priority and adequately reflected in the Country Coordinated Proposals.

The above is just a sampling of the guidelines in this document.¹⁰ It highlights some of the persistent challenges reported by U.S. PLHIV representatives serving on state and Eligible Metropolitan Area (EMA)-specific Ryan White Planning Councils and CDC-funded HIV Prevention Community Planning Groups, including the difficulties of:

- A. Building capacity for active, well-informed participation in decision-making bodies among a broad enough cross-section of the PLHIV population to assure that local constituencies have a diverse pool of interested and prepared candidates to choose from when selecting people to represent them;
- B. Assuring that the PLHIV representatives and alternates chosen are truly representative of our broader community and are selected by a process that is PLHIV-controlled;
- C. Making sure that our representatives are adequately resourced -- not only to travel to meetings but also to take time away from their income-generating activities without harm to themselves or their families; and
- D. Securing the staff and resources that PLHIV networks must have in order to hold regular consultations on the issues that our representatives will need to weigh in on. This

¹⁰ Ibid. Pages 70-73.

investment is essential to PLHIV representatives' ability to come prepared with primary position and back-up positions that are well defined, agreed in advance, and that reflect their constituency's perspectives.

Strategies for addressing Mechanism 1 Challenges

Strategy 1: Decision-making body must budget for, and invest substantially in, meaningful PLHIV representation

Ensuring authentic (rather than token) PLHIV representation requires substantial and sustained investment on the part of the decision-making entity to be effective. Sheer access to resources is the primary difference between the governmental and NGO entities that send representatives to the decision-making body and PLHIV networks seeking to send our own representatives.

NGOs and governmental organizations are generally made up of well-educated people with years (if not decades) of experience in attending decision-making meetings. They have salaries that cover the time they require not only to attend the actual meetings, but also to engage in the pre-meetings, informal consultations, and strategy calls that prepare them for effective meeting participation.

Most PLHIV networks, by contrast, are made up primarily of people who do not have these advantages or resources. To make it possible for all representatives to participate equally, therefore, substantial steps must be taken to level the playing field. PLHIV networks must be provided with what we need to address challenges A-D above on an on-going basis. Before the decision-making body even starts to meet, our networks must be given adequate time to select, build capacity, and prepare our representatives to serve on it. We also need the time and resources required to convene priority-setting consultations among our memberships, so that our representatives are fully prepared to present and defend their constituencies' positions.

HRSA is well aware of the need for such investment. One HRSA presentation noted, with regard to Ryan White Planning Councils, that "[m]ethods to enhance PLWH involvement include: policies and guidance requiring PLWH participation; technical assistance on-site and through special projects (workshops, training manual, national conference calls). HRSA policy encourages grantees to facilitate PLWH involvement by providing stipends, funds for transportation and childcare, and training on effective participation in the process."

The advent of NHAS, however, warrants a thorough assessment of how well various Planning Councils, CDC Prevention Planning Groups, and other federal grantees are actually adhering to federal guidance in this regard. Some state governments are reportedly declining to disclose how many PLHIVs are on their federally funded HIV policy planning groups and who they are¹¹, thus leading to the strong suspicion that they may have little or no PLHIV representation.

¹¹ Strub S. What happens in Mississippi no longer stays in Mississippi. 2010. Available at http://blogs.poz.com/cgi-bin/mt/mt-search.cgi?blog_id=42&tag=Brave%20New%20Day%20Mississippi%20Robin%20Webb%20pregnancy%20Denver%20Principles&limit=20

UNAIDS recommends that “[g]overnments, international agencies and civil society must set, implement and monitor minimum targets for the participation of people living with HIV, including women, young people and marginalized populations.”¹² This mention of the need for monitoring reminds us that “guidelines” for PLHIV involvement, without enforcement, may be insufficient.

Substantial, on-going, well-considered investment in a PLHIV-designed capacity-building plan is essential to leveling the playing field. Without conscientious effort in this direction, requiring on-going PLHIV representation in decision-making bodies is a good idea that quickly devolves into de-facto tokenism and meets with very limited real success. As Marijo Vazquez, a former Chair of the International Community of Women Living with HIV/AIDS (ICW), once wrote, “The only way you will empower me is if we sit at the table together and share our power.”¹³

Strategy 2: Recognize local decision-making entities as training grounds for effective advocates

Most of the PLHIV representatives currently serving on state and federal level decision-making bodies got experience in this type of initially through participation in local entities such as NGO boards of directors, consumer advisory groups convened by research institutions, local service evaluation initiatives, etc. Thus, encouraging or requiring such entities to actively solicit and include PLHIV participation actually serves two purposes. It not only fosters the valuable and ethically appropriate inclusion of PLHIV perspectives and expertise locally, but it also effectively recruits and trains people who may subsequently proceed to involvement in larger decision-making arenas.

Given this, it is cost-effective to allocate federal and state (as well as local) tax dollars -- and research institutions budget lines -- to fund ongoing efforts to recruit, train and support local PLHIV interested in serving on boards and advisory groups. Such individuals should also be engaged in implementing (not just providing input into) local service evaluation initiatives. The CDC's Medical Monitoring Project provides one example of diversified PLHIV involvement in service evaluation.

In addition to its immediate local value, such investment pays off by generating larger and better equipped pools of candidates for PLHIV seats at state and national decision-making tables.

Strategy 3: Form PLHIV Caucuses within Policy-Making Bodies

Many RWCA Planning Councils encourage PLHIV members to form their own caucus within the Planning Council. These are sometimes called Consumer Caucuses, or HIV+ Consumer Caucuses (since PLHIVs are not the only consumers of RWCA-funded services). These groups not only help to build mutual support for strong, collective PLHIV involvement but also help to strategize around how best to ensure broader-based consumer involvement in specific tasks such as needs assessment, evaluation, and developing the comprehensive plan.

¹² UNAIDS, Greater Involvement of People Living with HIV (GIPA). Policy Brief. 2007. Page 3. Available at http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

¹³ UNIFEM. Transforming The National Aids Response: Advancing Women's Leadership And Participation. July 2010. Available at http://www.unifem.org/attachments/products/Executive_Summary.pdf

Strategy 4: “Sign Off” policies

Despite best intentions, and even with the added strength of their own caucus, PLHIV representatives may still at times feel over-ruled and out-numbered by the full membership of the policy-making bodies in which they participate. One mechanism used to address this dynamic in some settings is requiring a “sign off” by the PLHIV Caucus, to assure that that group (even if outnumbered) still has some power to shape critical decisions and to insist on re-visiting decisions that they see as insufficient or unhelpful.

This process is similar to the concurrence process that the CDC requires between the Community HIV Prevention Planning Groups (CPG) they require and state or city health departments that they fund. The concurrence process is designed to assure that the health department's funding application accurately reflects the priorities set by the CPG.

Another example is the role played by the designated patient or consumer advocates who participate in federal FDA advisory panels. These panels review and approve (sign off on) or disapprove drug company applications, including pharmaceutical advertising language. The patient or consumer advocates on these panels often play key roles in persuading the panel to support or oppose licensure of a new drug, for example, or the language that a pharmaceutical company wants to use to promote it. While the FDA is not required by law to abide by the panel's recommendation, it usually does, because of the expertise behind those recommendations.

The controversy aroused by the “It's Never Just HIV” Public Service Announcement (PSA) released by the New York Department of Health and Mental Hygiene on 7 December 2010 illustrates the wisdom of such concurrence requirements. Although the New York City Health Department collected focus group input on the ad, they did not subject it to wider review and specifically did not seek assessment of it by their CDC-funded State HIV Prevention Planning Group. The subsequent reaction elicited by the PSA illustrates what can occur when significant sources of PLHIV input are not sought prior to major HIV/AIDS-related investment.

Mechanism 2

Consultations involving PLHIV (solely or as one among multiple constituencies).

This mechanism is used frequently and successfully both in the U.S. and internationally. The federal Office of National AIDS Policy and the Department of Health and Human Services (HHS) engaged on broad-based consultation with PLHIV and communities heavily impacted by HIV throughout its development of the NHAS. They held conversations with affected communities at conferences, through conference calls, and at a community consultation held in October 2010. They also collected input in writing and online via AIDS.gov blog comments.

While well-organized consultations can very effectively collect input on specific topics, they do have inherent limitations. Specifically they:

1. Allow PLHIVs to have input but do not give us any control over what is done with the information provided or the decisions that are finally made on the issue at hand.
2. Do not lend themselves to on-going information-sharing, debate, or evolutionary

discussion among the parties involved. The PLHIVs involved are advisory but are not the decision-makers. Consultations also tend to be convened as a “one-off” process and the information exchange is frequently a one-way street.

Strategies for addressing Mechanism 2 Challenges

These limitations are, for the most part, inherent in the structure of a consultation and can't be fully resolved. If a decision-making body engages in regularly-scheduled consultations with a PLHIV group, then that group is actually playing advisory role. It deserves to be recognized as an advisory council and receive the rights and responsibilities that attach to that role.

Consultations should be honestly acknowledged as what they are – valuable, one-time opportunities for PLHIV to give input on specific issues. Consultation output should be documented in thorough reports that are issued in a timely fashion. All consultation participants should receive a copy of the report *while it is still in draft form* and have adequate time to submit corrections to it. These corrections, if accurate, should be incorporated before the final version of the report is issued publicly.

For on-going forms of PLHIV involvement, other mechanisms cited in this paper should be used.

Mechanism 3

Innovative feedback mechanisms to assess services, policy implementation, etc.

Feedback mechanisms can enable PLHIV (both individuals and organizations) to be involved even when we do not want to – or don't have the time or resources to – engage at the level of serving on decision-making bodies or attending consultations. A few illustrative examples of effective feedback mechanisms include:

Report Cards

The Greater Involvement of People living with HIV/AIDS (**GIPA Report Card**), developed by GNP+, ICW and UNAIDS, is a questionnaire used to collect country-specific data indicating the degree to which national application of the GIPA principle is occurring. The GIPA Report Card report also suggests how PLHIV participation can be made more meaningful. It is completed by selected key informants, including NGOs working on PLHIV issues and data are also gathered through a review of the relevant literature. The GIPA Report Card is an accountability tool that establishes a baseline against which future national improvements will be measured.

In the U.S., the Positive Women's Network (PWN) and their allies developed a **Gender Monitoring Tool Report Card for the NHAS**. Its purpose is “to analyze the extent to which the NHAS identifies and prioritizes ways to improve all women's, including transgender women's, access to HIV prevention, care, and treatment programs consistent with the right to nondiscrimination, dignity, bodily integrity, and ethical treatment.”¹⁴

¹⁴ U.S. Positive Women's Network and Colleagues. Report Card: A Gender Monitoring Tool for the U.S. National HIV/AIDS Strategy. June 2010. Page 2. Available at <http://www.womenhiv.org/wp-content/uploads/2010/07/FINAL2-REPORT-CARD-NHAS-Gender-Audit-2010.pdf>

In 2010, thirteen organizations used this tool to do a gender audit of the NHAS. They identified the areas in which the rights of women living with, and at high risk of, HIV are most profoundly affected and graded the NHAS' anticipated capacity for impact in these areas.¹⁵ The audit also included participants' recommendations to "help guide the implementation of the Strategy toward a more effective response to the HIV epidemic among women in the U.S."¹⁶

Consumer Feedback Loops

In one recent survey of HIV/AIDS service programs in the U.S., 93% of them reported having feedback processes in place to gather consumer feedback on "program development, program implementation, and quality improvement".¹⁷ The tools used to do this included Patient Satisfaction Surveys, Patient Needs Assessments (asking patients what they need and which services are important to them), Consumer Focus Groups, and Client Liaisons. The latter is described as "one consumer acting as a bridge between the medical staff and the patients in the practice" because "[p]atients often feel more comfortable speaking with another consumer than with their own doctor. The liaison bridges the gap between staff and consumer."¹⁸

Funded by Washington DC Health Department, NAPWA operates a consumer advocacy program that supports independent, trained advocates to record consumer complaints and allow "residents to voice grievances about medical services they receive."¹⁹ Given that the Washington DC EMA is made up of 19 counties in the District of Columbia, Maryland, Virginia, and West Virginia – and has the highest HIV prevalence rate of any area in the country – the demand for such assistance is substantial. These consumer advocates impartially investigate grievance, negotiate resolution where possible, and report their recommended resolutions both to the service provider and the DC Administration for HIV Policy and Programs.

In this way, they not only assist individual PLHIVs in getting what they need but also build an evidence base showing chronic weaknesses and gaps in the local HIV/AIDS response and the impact that these deficits are having on people living with HIV/AIDS. By funding and operating the program through an advocacy organization (rather than a clinical care or service provider) and staffing it with independent, trained advocates, the Health Department minimizes the possibility of bias and maximizes the likelihood of gathering an accurate picture of how well medical services are meeting the needs of area residents.

Recently, a new tool called the Denver Principles Empowerment Index has been proposed to "provide a quantifiable measure of not-for-profit AIDS service providers' adherence to and fulfillment of self-empowerment ideals in their delivery of services, governance, development of

¹⁵ Ibid

¹⁶ Ibid

¹⁷ Chichocki M. Getting HIV Patients Involved: The Importance of Consumer Involvement in HIV/AIDS Care. January 2009. Available at <http://aids.about.com/od/advocatelinks/a/consumer.htm>

¹⁸ Ibid

¹⁹ NAPWA. Consumer Advocacy Program (CAP). 2009. Available at <http://napwa.webolutionary.com/content/consumer-advocacy-program-cap>

program and policy, advocacy and provision of HIV treatment information”²⁰. Using self-reported data provided voluntarily by AIDS service providers, the Index is designed to assess agencies in the five above-mentioned categories. The resulting reports would help communities to hold agencies accountable for meeting their stated goals.

The agency-provided data would be supplemented with a community ratings component allowing PLHIV to rank providers on factors that are critical to retaining us in on-going care; including the style of staff-client interactions, how appointments are scheduled, comfort of the physical setting, etc. While these opinions will not be objective, the component would help consumers to share our experiences with each other efficiently, just as Tripadvisor.com and other online tools allow travelers to seek advice and recommendations with other travelers.

Like the CDC's Medical Monitoring Project and other feedback tools, the Empowerment Index reports would also provide quality improvement data on care and treatment, especially regarding agencies' provision of treatment information. Finally, it would function as a philanthropic evaluation tool, much like Charitynavigator.com, by assisting foundations and other donors funders in determining how to use their money to support empowerment priorities.

Strategies for addressing Mechanism 3 Challenges

Cost is the biggest challenge associated with implementing any of the above techniques. It takes time, energy, and expertise to design and implement effective feedback mechanisms. Even the voluntary participation of PLHIVs in giving feedback is not free. Such voluntary feedback is only widely and effectively gathered when the implementing agencies have the outreach and follow-up resources required to stimulate a broad-based and representative response. The collected data must then be analyzed, published and disseminated before it can be acted upon. In the case of the liaison-based programs, staff time to research and negotiate resolution to the individual difficulties presented is also required.

People living with HIV have a pivotal role to play in the continuously improving the quality of the services they use. The information generated through use of the techniques described above can be invaluable. But, as elsewhere, the productivity realized is directly commensurate to the level of investment (in terms of time, money and commitment) put into it.

Mechanism 4

Hire PLHIV preferentially as needed to assure our adequate representation in policy-making and in the planning, delivery, and evaluation of HIV/AIDS services

In a 2009 commentary in the *Journal of the International AIDS Society*, three prominent leaders of PLHIV networks wrote that, “[i]n addition to contributing critical work in our communities, people with HIV have begun to participate in the governance structures of the Global Fund and other international bodies, **as well as in senior management and decision making roles**. But huge gaps remain at the national level. Governments, donors, National AIDS Control

²⁰ Strub S. “Denver Principles Empowerment Index”. 2011. Available at http://www.poz.com/pdfs/sos_empowerment_index_2011_07.pdf.

Programmes, lawmakers and nongovernmental organization-led HIV programmes need to open their doors to us.”²¹ (emphasis added)

The idea of HIV/AIDS decision-making bodies preferentially hiring PLHIVs for our personal perspectives, as well as our professional qualifications, is intellectually accepted but still not fully implemented in many circles. The NHAS notes that “three decades of experience tell us that essential starting points for addressing stigma and discrimination include maintaining a commitment to civil rights enforcement, working to ensure that public policies are grounded in best public health practices, and supporting people living with HIV to disclose their status and **promote the public leadership of community members living with HIV.**”²² (emphasis added) We are anxious to see whether the public leadership NHAS plans to promote will mainly involve PLHIV’s speaking from positions within our communities -- or whether this statement constitutes a public commitment to having PLHIV increasingly speaking from leadership positions within federal and state agencies.

Some national and state governments are already leading by example in this regard.

In India, the National AIDS Control Organization (NACO) *2010 GIPA Policy Guidelines for HIV Programmes* specify that, “[t]he GIPA Coordinator and Technical Officer at National AIDS Control Organisation will ensure integration of GIPA in various national and state programmes. A person from the community with suitable qualification and/experience shall be given the preference for the position of GIPA Coordinator.”²³ Among the many responsibilities of these two staffers is the establishment of a GIPA Technical Advisory Group at NACO, chaired by the Secretary and Director General.

On the domestic front, leadership has been shown by New York State, one of the first states in the US to establish a governmental entity solely dedicated to HIV/AIDS. The New York State Department of Health created the AIDS Institute in 1987 and Dr. Nicholas Rango, a physician living with HIV/AIDS, served as its first director. Since the early 1990s, the Institute has been committed to employing PLHIV on staff as consumer advocates. Currently, Dan Tietz serves as a Consumer Advocate for the Division of HIV Health Care and Policy.

Strategies for addressing Mechanism 4 Challenges

Two major challenges are often cited by U.S. state and federal government offices contemplating a policy of preferentially hiring PLHIVs who are open about their HIV status to work in programs that could benefit from their first-hand experiences with HIV. These are:

1. Concern about how this could be perceived in the context of existing affirmative action or non-discrimination policies. In fact, the Americans with Disabilities Act imposes no

²¹ Morolake O, Stephens D, Welbourne A. Greater involvement of people living with HIV in health care. *Journal of the International AIDS Society* 2009, 12:4. Available at <http://www.jiasociety.org/content/12/1/4>

²²The Office of National AIDS Policy. *The National HIV/AIDS Strategy for the United States*. July 2010. page 23. Available at www.WhiteHouse.gov/ONAP.

²³National AIDS Control Organization. *2010 GIPA Policy Guidelines for HIV Programmes*. 2010. Page 8. Available at http://www.nacoonline.org/upload/Mainstreaming/Draft%20GIPA%20Policy_for%20Comments.pdf

affirmative action obligations, but simply prohibits discrimination against a qualified applicant on the basis of disability.²⁴ Moreover, the U.S. Department of Labor website includes material that “[e]xplains why people with disabilities should be included in affirmative action programs and what contractors' affirmative action obligations are pertaining to outreach and recruitment of people with disabilities.”²⁵

2. Public attitudes. In a 2009 national survey of Americans, 23% reported that they would be uncomfortable working with a person with HIV or AIDS and only 44% rated themselves as comfortable or very comfortable with a PLHIV co-worker.²⁶

Actually, these two factors should bolster – rather than discourage – governments' commitment to employing qualified people who are openly living with HIV. As has been the case with every other area of affirmative action, stigma is broken down when people have the opportunity to get to know those whose presence challenges their pre-existing biases. The workplace provides, arguably, one the best environments for this.

Hiring people openly living with HIV to work in state and federal HIV/AIDS policy-making bodies is an integral step to improving our involvement in these programs, in part because such employment proves government's authentic commitment to the inclusion of PLHIV perspectives. It also constitutes practical, highly effective step that government can take to break down stigma simply by setting the right example.

We recommend that the Office of National AIDS Policy ask EEOC to explore the legal implications of determining that first-hand knowledge of HIV may be a legitimate area of expertise that warrants the preferential hiring of PLHIV for some positions or as some percentage of the staff in publicly funded agencies and/or policy-making entities.

Certainly, the postings of many public and private sector jobs related to HIV/AIDS include language indicating that PLHIV are encouraged to apply. This encouragement, however, does not carry the same weight as a legal opinion (if one were to emerge) recognizing that the unique experience of living with HIV was sufficiently valuable to the employer as to justify preferential hiring for that experience.

We also recommend that all HIV/AIDS service providers receiving public funding be required to examine the possibilities available to them for encouraging PLHIV to apply for jobs within their agencies. These possibilities include:

- Ensuring that people using their services are aware of job openings and know how to get information about the job's requirements and application process

²⁴ U.S. Equal Employment Opportunity Commission. *The ADA: Your Responsibilities as an Employer*. 2008. Available at <http://www.eeoc.gov/facts/ada17.html>

²⁵ U.S. Department of Labor. *Hiring: Affirmative Action*. Available at <http://www.dol.gov/dol/topic/hiring/affirmativeact.htm#doltopics>

²⁶ Lambda Legal. *HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report*. November 2010. Available at http://data.lambdalegal.org/publications/downloads/fs_hiv-stigma-and-discrimination-in-the-us.pdf

- Revising non-essential employment criteria that may be preventing some PLHIV from applying, such as requiring specific academic degrees, enforcing residency restrictions, or excluding viable candidates who have with criminal records
- Providing supplemental on-the-job training to current or former clients who are well-suited to existing openings
- Job sharing to accommodate health needs and/or family responsibilities of people who cannot work full-time

Mechanism 5

Require all publicly funded HIV/AIDS service providers to supply evidence (using standardized indicators) of their effective use of GIPA mainstreaming practices as a condition of their funding.

GIPA mainstreaming refers to moving from an *ideological commitment* to full integration of PLHIV perspectives into the publicly-funded AIDS response to the *actual practice* of this principle.

At the 2008 International AIDS Conference, Odhiambo and Lawson described the situation in Kenya in language that could apply today to many countries, including the U.S. They said that, “the Kenya National HIV/AIDS Strategic Plan, 2005-2010 (KNASP)... stipulates full involvement of PLHIV at all levels of the national HIV response. GIPA is not reflected in many strategies and policy documents of implementers, neither are GIPA indicators reflected in the national M&E framework. Hence, there is a need to mainstream GIPA into the overall HIV response to achieve the goals of KNASP”. These presenters, went on to note that “PLHIV have enormous potential to add dynamism and drive to the implementation of the KNASP, particularly with regard to prevention interventions and socio-economic mitigation initiatives, which will help avert HIV infections and enhance care and support. GIPA implementation provides a supportive environment for active engagement, ensures visibility of PLHIV, ethical response and rights based approach to the epidemic, thus increasing uptake of treatment and care services.”²⁷

As Odhiambo and Lawson indicate, one key element of successful GIPA mainstreaming is the use of effective monitoring and evaluation indicators. Only sporadic progress can be expected unless grantees are required, as a condition of their funding, to report regularly on the mechanisms they use to increase PLHIV involvement in their programming, the progress they have made, and the metrics by which they are monitoring and evaluating this progress.

The need for GIPA monitoring and evaluation is clear when we look at PLHIV involvement in Ryan White Care Act (RWCA) Planning Councils and CDC-funded HIV Prevention Community Planning Groups. In both cases, the grantee guidelines specify PLHIV involvement mechanisms that should be implemented. But the degree and rigor of implementation has been left almost entirely up to the individual states and EMAs. In many, substantial involvement has occurred .

²⁷ Odhiambo D, Lawson P. GIPA guidelines: a tool for mainstreaming GIPA into the HIV/AIDS national response in Kenya. AIDS 2008 - XVII International AIDS Conference: Abstract no. CDE0170. Available at <http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200715287>

But in others (as noted above), adherence to this guidance appears to have become lax and, in some cases, probably non-existent.

A Strategy for addressing the Mechanism 5 Challenge

The commencement of NHAS implementation is an opportune time to use the GIPA Report Card, or some comparably objective instrument, to do a baseline assessment of PLHIV involvement in a diverse sampling of states. This assessment could then be repeated periodically as a part of the NHAS' evaluation of progress toward its strategy targets. These assessments would tell us whether publicly funded entities are making adequate progress toward GIPA mainstreaming under the current federal guidances or whether evidence of such progress needed to be tied more tightly to future access to public funding.

With regard to agencies receiving federal HIV/AIDS funding, we strongly recommend that steps be taken to ensure that a set percentage of those serving on their boards or steering committee be PLHIV. This could be accomplished in one of two ways. One approach would be to make it a condition of funding. The other is to incentivize it by attaching it to access to some specific funding opportunities. Either approach would be preferable to inaction on this issue, as either will move some agencies that are not yet working to mainstream GIPA in that direction.

SOLUTION: GREATER INVESTMENT IN PEOPLE WITH HIV/AIDS

This briefing paper reflects a sense of urgency generated not only by HIV itself but also by the economic condition of the nation and by recent decisions by the federal government that could be interpreted as a declining commitment to PLHIV involvement, despite the language on it included in the NHAS. We note, for example, that the HRSA funding that previously supported Peer Education Training Site (PETS) initiatives has been re-assigned to other areas of work and no PETS RFP was released this year.

None of the mechanisms discussed above can be implemented without increased funding to support them. In a 2006 presentation, Ron MacInnes said that the acronym, GIPA, should actually stand for “Greater Investment in People with HIV/AIDS”, because “there cannot be greater involvement without greater investment”. He added that “greater involvement comes from greater capacity building”.²⁸ To make this imperative a reality, we should consider a re-framing of the issue proposed by the Collaborative Fund for HIV Treatment Preparedness.

Established in 2003, the Collaborative Fund is a partnership between the Tides Foundation and the International Treatment Preparedness Coalition. It describes itself as providing “financial support for associations of PLHIV and other community-based organizations to mobilize themselves and other key actors through an innovative community-driven funding mechanism. Grant recipients and their clients gain a better understanding of how to use HIV treatment effectively and learn to advocate effectively in their countries and communities for access to comprehensive treatment and care.”²⁹

The critical part of the Collaborative Fund’s rationale is essentially this:

- A. Adhering to treatment and prevention regimens successfully requires a lifelong commitment from the individuals most affected —the PLHIVs, themselves, and those at highest risk.
- B. This commitment cannot be achieved in the absence of “an equally strong commitment by other people, governments and organizations to support them, based on a clear understanding of their needs”³⁰.

THEREFORE

- C. The government, and the tax-paying citizens it serves, has a shared, vested interest in advancing GIPA goals. It is not just about human rights -- it’s also about public health. It’s not just about doing the right thing but also about doing the smart thing.

²⁸ MacInnes R. GIPA: The evolution of Leadership by People Living with and Affected by HIV/AIDS. Presentation to the International AIDS Society. 2006. Available at <http://www.iasociety.org/Web/WebContent/File/GIPA%20Presentation.pdf>

²⁹ Collaborative Fund for HIV Treatment Preparedness. People Living With HIV Leading the Way Toward Universal Access: The Collaborative Fund For HIV Treatment Preparedness. Report presented at the XVI International Conference on AIDS. 2006. Available at <http://quod.lib.umich.edu/c/cohen aids/5571095.0192.018>.

³⁰Ibid.

The Collaborative Fund focuses on supporting three priority areas:

- "HIV *treatment literacy and support*, through which individuals and communities gain capacity to make and follow through on HIV treatment decisions;
- *Treatment Advocacy* to overcome stigma and be able to access health information and care; and
- *Community Mobilization*, to ensure that local needs are voiced and heard, and that resources are appropriately allocated and used."³¹

These three elements, they argue, are essential elements to enabling communities and individuals to feel truly and personally invested in adhering to treatment and primary and secondary prevention practices.

Thus, it is a classic example of "doing good and doing well". The Collaborative Fund model demonstrates that the investment needed to help people become well-informed, effective advocates (which is the goal of authentic PLHIV involvement) is *the same investment* as that required to prepares PLHIVs to use treatment effectively, making them healthier and better at secondary prevention.

This model shows the necessity for equally strong commitments from both sides. Those living with HIV commit to treatment and prevention fully only when those in government commit to – and invest adequately in -- involving and engaging with them authentically.

This logic is a most compelling argument (even in the face of politically repressive forces and in an environment of economic constraint) for investing in GIPA. It shows that PLHIV involvement is, in fact, the key to stopping HIV.

³¹ Ibid