

INCREASING THE INVOLVEMENT OF HIV-POSITIVE WOMEN IN HIV ORGANIZATIONS

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Abbreviations

AIDS	acquired immune deficiency syndrome
APCASO	Asia-Pacific Council of AIDS Service Organizations
APN+	Asia Pacific Network of People Living with HIV/AIDS
ARV	antiretroviral
ASEAN	Association of South East Asian Nations
CBO	community-based organization
CCM	country coordinating mechanism
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CEDPA	Centre for Development and Population Activities
CIDA	Canadian International Development Agency
GIPA	greater involvement of people living with HIV/AIDS
GNP+	Global Network of People Living with HIV
HIV	human immunodeficiency virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social, and Cultural Rights
ICPD	International Conference on Population and Development
ICW	International Community of Women Living with HIV
IPPF	International Planned Parenthood Federation
MIPA	meaningful involvement of people living with HIV/AIDS
NAPWA	National Association of People Living with HIV/AIDS
NGO	nongovernmental organization
PLHIV	people living with HIV
PLWHA	people living with HIV/AIDS
SIDA	Swedish International Development Agency
STI	sexually transmitted infection
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNHCHR	United Nations High Commissioner for Human Rights
UNIFEM	United Nations Development Fund for Women
USAID	United States Agency for International Development
WAPN+	Women of APN+
WHO	World Health Organization

Increasing the Involvement of HIV-Positive Women in HIV Organizations

Who will use this guide?

This guide was developed at the request of the Asia Pacific Network of People Living with HIV (APN+) and Women of APN+ (WAPN+), a newly formed women's working group of APN+ that aims to empower women living with HIV in the Asia-Pacific region, with technical assistance from Dr. Susan Paxton. It was prepared for use by organizations run by and for people living with HIV (PLHIV) that offer support, services, or advocacy-related work, and is designed to help these organizations to examine how they can empower their women members, as well as integrate gender as part of the organization. Board members of HIV organizations can use the guide to examine their policies around gender equity, and program managers can use it when planning future programs.

The guide aims to

- Raise awareness of women's issues;
- Provide a user-friendly tool to assess the level of gender equity within organizations;
- Identify ways to enhance the involvement of women; and
- Support the promotion of gender equity in organizational policies and programs and in the communities served by the organization.

The guide outlines the meaning of gender equity and its importance, the rights of HIV-positive women, and the specific concerns they face. It also provides a questionnaire to examine the level of gender equity within the organization and some practical steps to address inequities. Useful references with electronic hyperlinks are included at the end of the guide.

Women understand, often more than the policymakers do, the real needs and issues at the community level. Specifically for women, I think [involvement in policymaking] is vital in terms of understanding gender dynamics in the epidemic. The burden that women face, if they are HIV positive, if they have family members who are HIV positive, is the burden of care. Often women carry a far heavier load than men do in relation to all issues: stigma and discrimination; care in the family; employment and income support ... That needs to be acknowledged at a policy level and it won't be acknowledged unless women living with HIV are involved in the policy debate.

~ Key NGO stakeholder, Southeast Asia

How can this guide be used?

PLHIV organizations and groups can use this guide at the time they are formed and throughout their organizational development. The process of addressing gender equity should be implemented on a scale that suits the type of organization—small or large, formal or informal. Members of the organization can read the guide's first sections on issues and rights and then use the questionnaire on pages 8–9 to assess the level of gender equity within their organization. If there is institutional resistance, a group of individual members may decide to do the assessment on their own and later present their findings to the organization as a whole. Women-only groups can also use this guide to determine how to increase women's involvement in policy and project design and implementation.

In carrying out a gender assessment, it is important to ensure leadership and participation in the process and to follow up with action. Members can use the questionnaire to assess the organization and then discuss the identified issues and create an action plan to address them.

The process should be participatory and include the voices of all members in open communication. It might be useful to form a committee to direct this process and to be responsible for

- Deciding when and to whom to distribute the questionnaire;
- Deciding who will analyze the results and how to share them;
- Setting priorities and planning follow-up actions, including deciding on who the actors will be and their roles and responsibilities;
- Raising funds to organize a gender training workshop; and
- Planning how to monitor and share outcomes of progress on action plans for gender equity.

What do we mean by gender?

Gender refers to the economic, social, political, and cultural attributes, and opportunities and constraints associated with being female and male. The social definitions of what it means to be female or male vary among cultures and changes over time. Most infants are born distinctly male or female and are then brought up to take on certain roles in society based on this sexual difference. Social, cultural, and religious norms generally dictate how men and women behave. Gender does not refer to the biological difference between men and women but rather the social and behavioral differences that identify men and women in society. It relates to the position of women and men in society in relation to each other and the power difference between them.

What do we mean by gender equity and gender equality?

Gender equity is the process of being fair to women and men, including using measures to compensate for historical and social disadvantages that prevent men and women from operating on level playing fields (CIDA, 1996). Gender equality is the state or condition that affords women and men enjoyment of human rights, socially valued goods, opportunities, and resources (SIDA, 1997). Women and men living with HIV have different needs. So, when we talk about gender equality, we are referring to whether all people—women, men, and transgenders—enjoy the same rights and opportunities; and if not, we need to examine ways to work toward gender equity.

Why do we need to address gender equity?

A lack of women's involvement is not unique to PLHIV organizations, but, rather, mirrors the situation within the general community. Women generally have a lower socioeconomic position than men. Women have a more difficult time ensuring that their needs are met and that their rights are respected, and they have less bargaining power. Due to these inequalities, an HIV-positive diagnosis hits women harder than their male counterparts. Women are more likely to be ostracized by families and communities, face physical violence, and lose access to property and other resources to support their needs.

Most HIV-positive activists understand the need for GIPA (the greater involvement of people living with HIV); and more recently, the term MIPA (the meaningful involvement of HIV-positive people) has been adopted and promoted. However, to date, "greater involvement" is generally being achieved primarily through an increase in involvement by men, not women. Worldwide, the majority of PLHIV organizations have more female than male members; however, men are typically the leaders of such organizations. Consequently, the specific concerns of women might not be adequately addressed. For example, many women in support groups are widows, who may have particular concerns about the well-

being of their children. Without meaningful involvement of women, this concern might not be a priority for the organization.

Furthermore, in decisionmaking committees, such as national AIDS committees or country coordinating mechanisms, men usually represent PLHIV. This means that the perspectives of women, regarding issues that many men might not think about, are often lost. Women have valuable perspectives to contribute, which might not be brought to light if their views are not considered. They face different challenges and experiences than their male counterparts in the areas of HIV prevention, care and support, and treatment. Thus women have valuable perspectives to contribute.

Despite the value of their input, HIV-positive women are often not taken seriously; their views are not considered important; and they are not on equal footing with men. Many women lack the confidence to express their needs openly or the skills to take on roles of greater responsibility within an organization. Some men under-value women's viewpoints or see women as victims. Women are often asked to represent only women's issues and, therefore, continue to be marginalized.

What issues are specific to women living with HIV?

The APN+ women's working group (WAPN+) has identified priority issues that affect the lives of HIV-positive women in the region, which are described below. To effectively address these issues, HIV-positive women must be involved in policy and program design.

Poverty

Women constitute the vast majority (approximately 70%) of the world's poor. HIV exacerbates poverty, and the number of HIV-positive women is increasing in relation to men throughout Asia and the Pacific. Many HIV-positive women are widowed; thus, they have to raise their children alone and often have inadequate income. HIV-positive women are also less likely to have opportunities for income generation. Female sex workers, who are already marginalized, are placed in an especially precarious position in terms of loss of income if they are known or suspected to be HIV positive.

All women should have the right to earn an income and be able to care for themselves and their children. In developing countries, because women generally have a lower skills base, and less access to or control over productive resources than men, there is a need to promote more income-generating schemes for women.

Discrimination and abuse

The APN+ documentation of HIV-related discrimination in Asia¹ noted that HIV-positive women are significantly more likely than their male peers to

- Face more discrimination from family and the community;
- Be excluded from family activities (sharing food, utensils, bedding, laundry, and bathing facilities, and playing with young children);
- Be banished from public places (shops, places of worship);
- Be forced to change housing or lose rights to property and inheritance; and
- Face physical violence.

¹ APN+. 2004. *AIDS Discrimination in Asia*. Accessible at <http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf>.

In addition to violence within relationships, women may also face intimidation and harassment within organizations. Violence toward women and threats of violence are unacceptable in any organization. Organizations should establish policies that address gender equity and nonviolence; and organizations should seek to recognize, prevent, and mitigate the specific stigma and discrimination that women face.

Lack of organizational skills

PLHIV networks in general suffer from lack of skills among both women and men. However, women in developing countries typically have lower literacy rates than men, and are less likely than men to have access to information technology. Thus, while women may be good at communicating and networking, they may lack the formal skills, opportunities, and confidence to help them move to more prominent positions within the organization. It is important to determine the skills or mentoring that women need, rather than assuming that particular skills training would be good for them. For example, depending on the organization, the following might be identified as areas in which women within a PLHIV group might want training skills:

- In the use of information technology
- How to operate an office
- How to run a support group
- How to speak publicly and conduct advocacy work
- How to counsel others
- How to serve on committees and be effective representatives

Access to healthcare

Many healthcare workers refuse to treat men and women known to be HIV positive. For women, this impedes access to good healthcare, particularly during pregnancy and labor and immediately after childbirth. Women's higher rates of illiteracy may also result in women missing out on crucial health education information. It is important to facilitate access to information—particularly via well-resourced peer support groups that allocate time for visits by experts, during which women can ask questions.

Some women may have difficulty accessing appropriate antiretrovirals (ARVs), treatment for opportunistic illness, HIV monitoring, and services to prevent HIV transmission to children during pregnancy and delivery. The reasons vary: government programs may not be offered nearby; and women may not be able to afford the transportation to the healthcare center that provides ARVs. In some cases, husbands were found to “take” women's ARVs, so that they do not have to go to the health clinic themselves. In many families, priority for healthcare is given to men. These challenges must be addressed to improve access to healthcare for HIV-positive women.

Sexual and reproductive health

HIV-positive women are often unaware of the sexual and reproductive health resources available to them. In many cultures, women are expected to not have sex until marriage, and open discussion about women's sexual and reproductive health issues is limited. Women who carry condoms can be accused of being “immoral.” Women are the ones who get pregnant, but they are usually given little information and choice around their own reproductive health. Women are more susceptible than men to sexually transmitted infections (STIs) and, when asymptomatic, they may go undiagnosed and untreated. Many women diagnosed as HIV positive during pregnancy do not tell their partners because of fear of abandonment or violence, and in many instances, they hesitate to access healthcare services for fear of discrimination.

For most women, only a few contraceptive options (including intrauterine devices) are available. Although condoms provide dual protection against pregnancy and STIs, few women are able to negotiate their use, even if the condoms are accessible and available. Not only do women need more reproductive health options, they also need to be fully informed about the family planning choices that are under their control (including female condoms, oral hormonal contraceptives, injectables, and implants—all of which are safe for most HIV-positive women). This information will enable women to prevent unintended pregnancies and to exercise greater control over their reproductive health. Currently, several microbicides are being tested, which may ultimately provide alternatives for women to protect themselves from STIs, HIV, and unintended pregnancies.

In some cases, if they become pregnant, HIV-positive women are coerced into terminating the pregnancy. HIV-positive women are rarely provided with accurate information on having healthy pregnancies. For example, women living with HIV may not realize the importance of lowering their viral load to undetectable levels during pregnancy. Also, some doctors recommend that women stop ARV treatment during the first trimester of pregnancy because of fears that ARVs may damage the fetus. This is actually a misconception and, in fact, greatly increases the risk of transmitting HIV to the unborn infant because of a rebound in viral load when the mother stops taking ARVs. Women need information about ARVs for themselves and their infants, as set out in the World Health Organization (WHO)/United Nations Population Fund (UNFPA) guidelines on the sexual and reproductive health of women living with HIV.² In addition, women living with HIV need greater access to postpartum care and information on the risks and benefits of exclusive breastfeeding.

Legal issues

Women may need expert legal advice on a range of issues:

- Marital sexual assault or rape in marriage
- Police harassment
- Widow disinheritance, including property rights
- Child custody
- Unlawful dismissal from employment
- Sexual harassment in the workplace
- Eviction from housing
- Breaches of confidentiality

What rights do women have?

Women should enjoy the same rights as men. The Universal Declaration of Human Rights, adopted by the United Nations (UN) General Assembly in 1948, asserts that every person has the right to “life, liberty and security of person, equal pay for equal work, a standard of living adequate for health and well-being, education, freedom from slavery, and equal protection of the law.” The rights outlined in the declaration were later included in the first two major international covenants on human rights: the International Covenant on Economic, Social, and Cultural Rights (ICESCR);³ and the International Covenant on Civil and Political Rights (ICCPR).⁴ These treaties recognize the equal rights of men and women to the following:

² WHO/United Nations Population Fund (UNFPA). 2006. *Sexual and Reproductive Health of Women Living with HIV/AIDS: Guidelines on Care, Treatment, and Support for Women Living with HIV/AIDS and their Children in Resource-Constrained Settings*. Accessible at http://www.unfpa.org/upload/lib_pub_file/616_filename_srh_hiv-aids.pdf.

³ The ICESCR can be used as a tool to promote economic, social, and cultural rights in the 158 countries that have ratified the treaty.

⁴ The ICCPR can be used as a tool to promote civil and political rights in the 160 countries that have ratified the treaty.

- An adequate standard of living, including adequate food, clothing, and housing and continuous improvement in living conditions (ICESCR, Article 11)
- The highest attainable standard of health (ICESCR, Article 12)
- The benefits of scientific progress (ICESCR, Article 15)
- Education (ICESCR, Article 13)
- Work (ICESCR, Article 6)
- Sexual non-discrimination (ICCPR, Article 2)
- Privacy (ICCPR, Article 17)

Women’s equal rights are recognized in various declarations, including the Convention for the Elimination of All Forms of Discrimination against Women (CEDAW),⁵ adopted by the UN General Assembly in 1979. The first human rights treaty to specifically outline and affirm the rights of women, it prohibits discrimination based on sex and encourages equal access to healthcare services (see Box 1).

The UN Convention on the Rights of the Child (UNCRC),⁶ written in 1989, seeks to protect young people under 18 years old, including protection from incest, trafficking, and sexual slavery; and states that the rights of the child are paramount.

At the UN World Conference on Human Rights in Vienna, Austria, in 1993,⁷ women’s rights were again reaffirmed as human rights. The Vienna declaration noted deep concerns about the discrimination and violence that women continue to experience all over the world. The document was the first declaration to recognize violence against women, including domestic violence, as a human rights issue. It calls for the elimination of violence against women in public and private life. It also states:

The human rights of women and of the girl child are an inalienable, integral, and indivisible part of universal human rights. The full and equal participation of women in the political, civil, economic, social, and cultural life at the national, regional, and international levels, and the eradication of all forms of discrimination on grounds of sex are priority objectives of the international community.

The UN General Assembly adopted the Declaration on the Elimination of Violence against Women in 1993. It is the first international human rights instrument to exclusively and explicitly demand elimination of all forms of violence against women and a commitment of member states to carry out their responsibilities in ensuring the protection of women’s rights. It states that violence against women is “any act of gender-based violence that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life.”

In 1994, the International Conference on Population and Development (ICPD)⁸ called attention to the need to recognize women’s reproductive health as a high-priority, international health and development issue. Adopted by 179 countries, the ICPD can be a useful tool in promoting equitable access to comprehensive reproductive healthcare in many developing countries.

⁵ CEDAW can be used as a tool to promote women’s rights in the 185 countries that have ratified the convention.

⁶ The UNCRC can be used as a tool to promote children’s rights in the 193 countries that have ratified it.

⁷ About 170 countries participated in the World Conference on Human Rights in Vienna in 1993. The UN also established the High Commissioner for Human Rights in 1993.

⁸ All discussion on the content and commitments of the ICPD declaration pertain only to those countries where the declaration has been signed.

The Beijing Platform for Action,⁹ in 1995, called on all key stakeholders to “ensure the involvement of women, especially those infected with HIV... in all decisionmaking relating to the development, implementation, monitoring, and evaluation of policies and programs on HIV/AIDS.”

In 2000, the UN established the Millennium Development Goals, which include reducing child mortality, improving maternal health, and reducing the transmission of HIV by 2015. The related declaration, signed by all member states, coupled with the development of cheaper, generic ARVs, spurred a focus on testing pregnant women for HIV to prevent transmission during pregnancy. These programs have accelerated globally, often without due consideration of the consequences to the woman and her family in diagnosing an HIV-positive status during pregnancy. For example, women, who are diagnosed before their husbands, may be blamed for bringing HIV into the family. These programs appear to have been driven by medical researchers and do not reflect a holistic approach to maternal health.

In 2001, the UN General Assembly Special Session’s (UNGASS) Declaration of Commitment on HIV/AIDS stated that, by 2005, all member states should “develop and accelerate the implementation of national strategies that promote the advancement of women and women’s full enjoyment of all human rights; promote shared responsibility of men and women to ensure safe sex; empower women to have control over and decide freely and responsibly on matters related to their sexuality....” Countries are still working to accomplish these objectives.

In 2004, member countries of the Association of South East Asian Nations (ASEAN) signed two declarations that further support the UN treaties to protect women’s rights: the “Declaration on Elimination of Violence against Women in ASEAN countries,” which urges each member country to fully implement the goals and commitments made related to eliminating violence against women and monitor their progress; and the “ASEAN Declaration against Trafficking in Persons, Particularly Women and Children,” which intensifies efforts to address transnational trafficking.

Despite these internationally binding declarations and treaties, women’s rights and, in particular, HIV-positive women’s rights, are often not respected throughout the Asia-Pacific region; and women diagnosed with HIV experience significantly more discrimination than men do.¹⁰ Until women are given full and accurate information about their rights and the ability to advocate for them, they will be unable to exercise their choices to live full, enjoyable, and healthy lives. By ignoring women’s voices, programs will not address the needs of the whole community and, thus, will only have a limited impact.

⁹ Nearly 190 governments participated in the Fourth World Conference on Women in 1995, resulting in the Beijing Declaration and Program of Action, which were adopted by consensus.

¹⁰ APN+. 2004. *AIDS Discrimination in Asia*. Accessible at <http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf>.

Box 1. Treaties of Particular Relevance to Women

The **Convention for the Elimination of All Forms of Discrimination against Women** places the rights of women on an equal basis with men, including the right to

- Health (Article 12)
- Choose a spouse and to decide freely and responsibly on the number and spacing of children and to have access to the information, education, and means to enable them to exercise those rights (Article 16)
- Education (Article 10)
- Work (Article 11)
- Obtain financial credit (Article 13)
- Own and dispose of property (Article 16)

All countries in the Asia-Pacific region have ratified this treaty, with the exception of North Korea. This means that governments have agreed to uphold these rights for all their citizens. Unfortunately, most governments have not made adequate efforts to ensure women's rights are respected. Nevertheless, the fact that governments have signed CEDAW can be used as an advocacy tool to push those in power to respond to violations of women's rights.

The **Declaration on the Elimination of Violence against Women**, Article 3, states that women are entitled to the equal enjoyment and protection of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. They include the right to

- Life
- Equality
- Liberty and security of person
- Equal protection under the law
- Freedom from all forms of discrimination
- The highest attainable standard of physical and mental health
- Just and favorable conditions of work
- Freedom from torture or other cruel, inhuman, or degrading treatment or punishment

How gender equitable is your organization?

Due to the specific concerns and perspectives that women have related to HIV, PLHIV organizations, groups, and networks must address the needs of women and involve women at all levels of decisionmaking. Organizations should begin by asking themselves: "Are we sensitive to issues concerning gender?" The following questionnaire includes 33 questions to help organizations determine the extent to which they are sensitive to gender issues.

Questionnaire to Determine an Organization's Sensitivity to Gender

Answer each question by circling the appropriate number (or letter)

1 = never, 2 = sometimes, 3 = often, 4 = always, U = unsure

1. Does the organization welcome women as members?	1	2	3	4	U
Provision of information					
2. Is information available to women about their rights?	1	2	3	4	U
3. Does the organization offer any information specific to women's health (e.g., cervical pap smears, contraception, pregnancy, potential interactions between ARVs and other drugs)?	1	2	3	4	U
4. Is information delivered in an appropriate way so that women can understand it?	1	2	3	4	U
5. Does the organization provide information on the importance of gender equity as it relates to sexual and reproductive health?	1	2	3	4	U
6. Does the organization have any referral systems for women (e.g., for sexual and reproductive health, ARVs, food, counseling, legal help)?	1	2	3	4	U
7. Does the organization facilitate links among women and the International Community of Women living with HIV (ICW), the women's working group of APN+ (WAPN+), national networks of women where they exist, or other women's organizations?	1	2	3	4	U
Service provision					
8. Does the organization provide opportunities for women to meet to discuss their issues?	1	2	3	4	U
9. Does the organization offer specific services to women?	1	2	3	4	U
10. Has the organization made links with other organizations that address women's specific needs?	1	2	3	4	U
11. Does the organization consider and address whether women face certain constraints that may limit their access to services?	1	2	3	4	U
12. Does the organization actively seek to address gender inequality and empower women in all key programs?	1	2	3	4	U
Involvement in programs					
13. Does the organization encourage women to voice their needs and concerns?	1	2	3	4	U
14. Are there any organizational policies to ensure that women's voices are heard?	1	2	3	4	U
15. Are women appropriately informed of meetings and events?	1	2	3	4	U
16. Are women involved in designing the organization's policies and programs?	1	2	3	4	U
17. Are women involved in implementing any programs?	1	2	3	4	U
18. Are women involved in monitoring the organization's programs?	1	2	3	4	U
19. Does the organization have any strategies to recruit and involve women?	1	2	3	4	U

20. Does the organization have any policies that clearly and unambiguously reject violent behavior toward women?	1	2	3	4	U
21. Is childcare available to facilitate women's involvement?	1	2	3	4	U
Skills building					
22. Are women consulted about what skills they need?	1	2	3	4	U
23. Are women offered opportunities to increase their skills base?	1	2	3	4	U
24. Does the organization conduct training workshops where at least 50 percent of participants are women?	1	2	3	4	U
25. Are women trained and supported to deliver workshops and facilitate meetings themselves?	1	2	3	4	U
26. Are men trained on gender equity and provided opportunities to learn how to promote gender equity and share power?	1	2	3	4	U
Leadership and representation					
27. Does the organization project positive images of women?	1	2	3	4	U
28. Do women hold positions of responsibility in the organization?	1	2	3	4	U
29. Do women hold representative positions in the organization?	1	2	3	4	U
30. Do women frequently represent the organization in public?	1	2	3	4	U
31. Do women attend meetings on behalf of the organization with government, donors, NGOs, UN agencies?	1	2	3	4	U
Governance					
32. Are half of the positions on the board of management of the organization occupied by women?	1	2	3	4	U
33. Is there gender balance in the executive positions on the board?	1	2	3	4	U
Add up the total score. If several people in the organization completed the questionnaire, add up all the scores and calculate the average score. Scores of 100 points or more indicate that an organization has managed to integrate gender issues into many of its programs. Otherwise, there is work to do.					

After completing the questionnaire and reviewing the extent of gender equity within the organization, consider what needs to be done in the following areas:

- Membership
- Information provision
- Program implementation
- Skills building
- Employment
- Governance and representation
- Access to ARVs and treatment for opportunistic infections
- Access to sexual and reproductive healthcare

Then look at how the organization can redress any imbalance. For example, the organization might need to conduct gender training for all its members. Such training might seek to improve members' capacity in understanding gender concepts, identifying gender-related issues, and integrating gender into existing and

future programs within the organization. Specific training related to the relation between gender and HIV might also be necessary, so that members can identify and respond to issues related to both concepts, and determine concrete interventions to address them in programming and advocacy work as part of the organization. The gender training module produced by Ipas¹¹ might be useful for this effort.

How can organizations ensure gender equity?

The following steps can also be taken to improve gender equity:

Consult women in the organization to assess their needs

- Call a meeting of all members and ask them about their most urgent issues.
- Discuss the organization's mission.
- Ask the group how the organization can help women to address their issues.
- Determine which issues are easiest to address, and which will have greatest impact.
- Assess the number of women within decisionmaking bodies.
- Identify barriers women currently face in being involved in HIV leadership and advocacy—in the organization and in other settings.
- Identify skills or other support/resources/organizational changes women need to be more involved in HIV leadership and advocacy and to carry out their roles more effectively.
- Prepare an action plan.
- Identify who can help achieve objectives and how.
- Determine funding needs to carry out any proposed projects.
- Identify what donors to approach to support the organization's plans.
- Identify other women's groups that exist in the locality.
- Carry out a stakeholder analysis.

Provide an opportunity for the formation of women's groups

The dynamics of women's discussions can change dramatically if men are present. Many women feel safe to speak out within a women-only group and might be reluctant to speak frankly or openly if men are present.

- Support women-only gatherings.
- Provide opportunities for women to meet regularly.
- Use the ICW's *Positive Women's Survival Kit*¹² to address particular issues. Women can read a chapter of the kit each month and then discuss the issues raised.

Provide appropriate information

Many NGOs and government schemes have programs that address gender inequality and/or advocate for improved conditions for women. Investigate which NGOs are working with women in the Asia-Pacific region, and make proactive choices about which organizations you want to align with.

- Adapt available information, such as the WHO/UNFPA guidelines on sexual and reproductive health of HIV-positive women, into an accessible, user-friendly format and translate the document into the local language.

¹¹ De Bruyn, M., and N. France. 2001. *Gender or Sex: Who Cares? Skills-Building Resource Pack on Gender and Reproductive Health for Adolescents and Youth Workers—With a Special Emphasis on Violence, HIV/STIs, Unwanted Pregnancy, and Unsafe Abortion*. Chapel Hill, NC: Ipas. Accessible at http://www.ipas.org/Publications/Gender_or_sex_Who_cares.aspx?ht.

¹² ICW. 1999. *A Positive Woman's Survival Kit*. Accessible at <http://www.icw.org/files/Survival%20Kit.pdf>.

- Create a body of up-to-date, accessible information for women. Women particularly want information pertaining to sexual and reproductive health, childcare, nutrition, and income generation activities.
- Facilitate improved communication among women. For example, it may be most appropriate to use the telephone to contact women, rather than e-mail, to which they may have limited access.
- Strengthen partnerships with organizations working with women.

Strengthen the capacity of women

- Ask women what training they want.¹³ Based on experience from past meetings of WAPN+, women in the Asia-Pacific region have expressed the need for training in the following areas:
 - ❖ Advocacy and rights
 - ❖ Treatment literacy
 - ❖ Reproductive health
 - ❖ Training-of-trainers to gain confidence to facilitate meetings and trainings
- Make sure women are included in all activities.
- Investigate opportunities for enhancing women's skills.
- Offer training workshops and skills building specifically for women.
- Provide training so women can educate their families, communities, and influential leaders about HIV-related discrimination and their rights.
- Advocate for NGOs to write funding proposals for women's projects, including for capacity building and income generation. International donors are often open to projects that increase women's empowerment.
- Build skills of women so they can write their own funding proposals.
- Explore ways to contribute to the documentation of in-country compliance with international treaties, such as CEDAW.

Create income-generating opportunities for women

There is a need to address women's lack of access to productive resources and control over household income. Advocate to government and NGOs to provide employment to HIV-positive women. Explain the benefits of GIPA to a successful response to HIV and the need to employ women—particularly as counsellors and educators—to create more positive images of PLHIV, reduce HIV-related stigma and discrimination, and raise awareness about the whole population's vulnerability to HIV.

- Help HIV-positive women to identify sustainable income-generation programs available to them.
- Work closely with NGOs to research income-generation opportunities for women.
- Advocate with international donors to fund women's income-generating projects and micro-credit schemes. These schemes can be promoted as a way to counter stereotypes and advocate to communities that HIV-positive women can be active and productive members of society.
- Facilitate exposure visits to other projects if possible.
- Explore avenues for vocational training. Sometimes women may need only a short course (e.g., in computers, counseling,¹⁴ sewing) to gain the skills and confidence needed to obtain employment or generate their own income. Ask women what skills they would like to acquire.
- Investigate funding possibilities to enable women to gain these vocational skills.

¹³ Useful references to various toolkits and training manuals are provided at the end of this document.

¹⁴ APN+/Australian Red Cross. 2005. *Asia Pacific Participant's Manual and Training Resource on Basic HIV Counseling Skills*. Accessible at <http://www.apnplus.org/document/Asia%20Pacific%20Participant's%20Manual%20and%20Training%20Resource%20on%20Basic%20HIV%20Counseling%20Skills.pdf>.

- Assess other financial avenues of support. Learn about all available social security assistance from the government and NGOs and refer women who are particularly disadvantaged financially.

Develop policies and implement strategies to overcome organizational barriers to women's meaningful involvement

Once the organization has examined and identified the challenges to women's equal involvement and participation in leadership, members should devise innovative ways to proactively address these challenges. For example, if childcare is an issue, women could bring children to meetings and/or have a rotational childcare roster. If women lack specific skills that other members have, the organization could hold "teach-ins," where members share their skills or outside volunteers offer their time to help in training and skills development among women. If the organization has an office, information technology classes could be held there outside business hours.

- Develop policies that ensure gender equity in all programs. Organizations need to encourage and support women's involvement in all aspects of their work—from designing and implementing programs to policy development and decisionmaking at all levels.
- Examine what policies, if any, exist in the country in relation to gender equity; and discuss whether they can be usefully adapted to address the needs of women in the organization.
- If the organization employs women, ensure that women have equal opportunities and conditions within the workplace.
- Help to increase women's access to ARVs and drugs for opportunistic infections. Improve HIV-positive women's ARV treatment literacy by providing readily accessible and understandable treatment information and training.¹⁵
- Formulate policies to protect women from violence and harassment. Advocate against gender-based violence. Intimidating behavior is also unacceptable, as is sexual harassment.
- Create opportunities for everyone to voice their concerns in a safe environment.
- Develop conflict resolution policies. Have clear guidelines in relation to acceptable and unacceptable behavior and stick to them. If possible, neutral mediators should be brought in to resolve difficult conflicts.
- Implement other ways to address gender equity.

Ensure that both women and men are represented in the organization

- Encourage women and men to share representative positions. Or, for every representative position held by a man, ensure a woman is encouraged to act as a co-representative, to allow for women's perspectives to be heard. Make sure she is well-informed of all the work involved in and the responsibilities expected of the representative position.
- Use APN+'s organizational development manuals¹⁶ to help members understand how to strengthen their organization.
- Increase women's participation in national HIV committees, country coordinating mechanisms of the Global Fund, and committees monitoring universal access targets.
- Change the organization's by-laws to reflect gender equity. The by-laws of the organization should reflect gender equity by having at least 50 percent of board member positions held by women and 50 percent of executive positions held by women. Any changes to the by-laws will

¹⁵ SafAIDS. 2005. *A Treatment Literacy Toolkit: A Part of Every Woman*. Harare, Zimbabwe: SafAIDS. <http://www.safaid.net/?CFID=12697706&CFTOKEN=57022885>

¹⁶ APN+ and National Association of People Living with HIV/AIDS (NAPWA/Australia). 2003. Organizational development manuals: (1) Project planning and evaluation, (2) Obtaining funding, (3) Governance and accountability. Retrieved in December 2007 at http://www.apnplus.org/home/index.php?option=com_docman&task=cat_view&gid=15&Itemid=26.

need to be made at a special general meeting and ratified by the membership, with appropriate notice of all changes given to members beforehand.

Provide mentoring for women

In addition to gaining skills, mentoring should focus on strengthening women's capacity to take on leadership roles. Mentoring means having an experienced person to guide someone through a process over time. Mentoring is usually a one-to-one relationship. It might involve regular meetings of the mentor and trainee to talk through issues or areas in which the woman feels she lacks confidence or experience.

- Identify mentors for women.
- Assess which organizations or people would be suitable to mentor women so they can become more confident as decisionmakers; and approach the organizations/individuals for assistance.

How can I obtain further assistance?

APN+ can provide technical assistance to help implement a review of gender issues, either by identifying possible donors or referring organizations to HIV-positive facilitators. For more information on any of the issues raised in this module, contact the regional office of APN+:

APN+
176/22 Sukumvit Soi 16, Klongtoey
Bangkok, 10110, Thailand
Tel: +66 2 259 1908-9; Fax: +66 2 259 1906
www.apnplus.org

What are some useful resources?

Toolkits and training manuals

Asia Pacific Network of People Living with HIV (APN+). 1999. *Lifting the Burden of Secrecy: A Manual for HIV-Positive People Who Want to Speak Out in Public*. Bangkok, Thailand: APN+.
<http://www.apnplus.org/webpage/Publications.html>.

APN+ and National Association of People Living with HIV/AIDS (NAPWA/Australia). 2003. Organizational development manuals. 1: Project planning and evaluation; 2: Obtaining funding; 3: Governance and accountability. Retrieved in December 2007 at
http://www.apnplus.org/home/index.php?option=com_docman&task=cat_view&gid=15&Itemid=26.

APN+/Australian Red Cross. 2005. *Asia Pacific Participant's Manual and Training Resource on Basic HIV Counseling Skills*. Bangkok, Thailand: Australian Red Cross.
<http://www.apnplus.org/webpage/Publications.html>.

APN+/Asia-Pacific Council of AIDS Service Organizations (APCASO). 2006. *Valued Voices: GIPA Toolkit—A Manual for the Greater Involvement of People Living with HIV/AIDS*. Bangkok, Thailand: APN+.
<http://www.apnplus.org/webpage/Publications.html>.

De Bruyn, M. 2006. *Fulfilling Reproductive Rights for Women Affected by HIV: A Tool for Monitoring Progress Toward Three Millennium Development Goals*. Updated Version. Chapel Hill, NC: Ipas.
http://www.ipas.org/Publications/asset_upload_file245_2897.pdf.

De Bruyn, M., and N. France. 2001. *Gender or Sex: Who Cares? Skills-Building Resource Pack on Gender and Reproductive Health for Adolescents and Youth Workers—With a Special Emphasis on Violence, HIV/STIs, Unwanted Pregnancy, and Unsafe Abortion*. Chapel Hill, NC: Ipas.
http://www.ipas.org/Publications/Gender_or_sex_Who_cares.aspx?ht.

EngenderHealth. 2004. *Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers*. New York, NY: EngenderHealth.
<http://www.engenderhealth.org/res/offc/hiv/stigma/index.html#stigma>.

EngenderHealth/International Community of Women Living with HIV (ICW). 2006. *Sexual and Reproductive Health for HIV-Positive Women and Adolescent Girls: Manual for Trainers and Program Managers*. New York and London: EngenderHealth and ICW.
http://www.engenderhealth.org/aids/pdfs/tech-library/hiv/SRH_for_HIV_Positive_Women.pdf.

ICW. 1999. *A Positive Woman's Survival Kit*. London: ICW.
<http://www.icw.org/files/Survival%20Kit.pdf>.

ICW. 2006. *Positive Women Monitoring Change: A Monitoring Tool on Access to Care, Treatment, and Support; Sexual and Reproductive Health and Rights; and Violence against Women Created by and for HIV-Positive Women*. London: ICW. <http://www.icw.org/files/monitoringchangetool-designed.doc>.

International HIV/AIDS Alliance. 2002. *Advocacy in Action: A Toolkit to Support NGOs and CBOs Responding to HIV/AIDS*. Brighton, UK: International HIV/AIDS Alliance.
http://www.aidsalliance.org/graphics/NGO/documents/english/418_advocacy_in_action.pdf.

SafAIDS. 2005. *A Treatment Literacy Toolkit: A Part of Every Woman*. Harare, Zimbabwe: SafAIDS.
<http://www.saf aids.net/?CFID=12697706&CFTOKEN=57022885>.

Swedish International Development Agency (SIDA). 1997. *Handbook for Mainstreaming: A Gender Perspective in the Health Sector*. Stockholm, Sweden: Department for Democracy and Social Development, Health Division.

United Nations Development Fund for Women (UNIFEM). 2000. *Gender, HIV, and Human Rights: A Training Manual*. New York, NY: UNIFEM.
http://hivaidsclearinghouse.unesco.org/ev_en.php?ID=1953_201&ID2=DO_TOPIC.

Guidelines

Canadian International Development Agency (CIDA). 1996. *Guide to Gender-Sensitive Indicators*. Ottawa, Canada: CIDA.

Global Network of People Living with HIV (GNP+) and POLICY Project. 2005. *Challenging, Changing, and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms*. Amsterdam and Washington: GNP+ and POLICY Project/Constella Futures.
<http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf>.

Ipas. 2003. *Integrating HIV and Safe Abortion Care: Vision, Guiding Principles, and Recommendations for Action*. Chapel Hill, NC: Ipas. http://www.ipas.org/Publications/asset_upload_file935_2441.pdf.

UK Consortium on AIDS and International Development. 2003. *Working Positively: A Guide for NGOs Managing HIV/AIDS in the Workplace*. London: UK Consortium on AIDS and International Development.

http://www.aidsalliance.org/graphics/secretariat/publications/ukconsortium1203_working_positively.pdf.

United Nations Joint Program on HIV/AIDS (UNAIDS) Inter-Agency Task Team on Gender and HIV/AIDS. 2005. *Operational Guide on Gender and HIV/AIDS. A Rights-Based Approach*. Amsterdam: UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS.

<http://www.unfpa.org/publications/detail.cfm?ID=279&filterListType=1>.

World Health Organization (WHO)/United Nations Population Fund (UNFPA). 2006. *Sexual and Reproductive Health of Women Living with HIV/AIDS: Guidelines on Care, Treatment, and Support for Women Living with HIV/AIDS and their Children in Resource-Constrained Settings*. Geneva: WHO.

http://www.unfpa.org/upload/lib_pub_file/616_filename_srh_hiv-aids.pdf.

International and regional declarations

Association of South East Asian Nations (ASEAN). 2004. "Declaration on the Elimination of Violence against Women in the ASEAN Region." <http://www.aseansec.org/16189.htm>.

ASEAN. 2004. "ASEAN Declaration against Trafficking in Persons, Particularly Women and Children." <http://www.aseansec.org/16793.htm>.

United Nations Office of the High Commissioner for Human Rights (UNHCHR). 1966. "International Covenant on Civil and Political Rights." http://www.unhchr.ch/html/menu3/b/a_ccpr.htm.

UNHCHR. 1966. "International Covenant on Economic, Social, and Cultural Rights." http://www.unhchr.ch/html/menu3/b/a_cescr.htm.

UNHCHR. 1979. "Convention on the Elimination of All Forms of Discrimination against Women." <http://www.unhchr.ch/html/menu3/b/e1cedaw.htm>.

UNHCHR. 1989. "Convention on the Rights of the Child." <http://www.unhchr.ch/html/menu2/6/crc/treaties/crc.htm>.

United Nations General Assembly. 1993. "Vienna Declaration and Program of Action." [http://www.unhchr.ch/huridocda/huridoca.nsf/\(Symbol\)/A.CONF.157.23.En](http://www.unhchr.ch/huridocda/huridoca.nsf/(Symbol)/A.CONF.157.23.En).

United Nations General Assembly. 1993. "Declaration on the Elimination of Violence against Women." <http://www.un.org/documents/ga/res/48/a48r104.htm>.

United Nations General Assembly Special Session. 2001. "Declaration of Commitment on HIV/AIDS." <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>.

United Nations Fourth World Conference on Women, Beijing. 1995. "Platform for Action." <http://www.un.org/womenwatch/daw/beijing/platform/>.

Reports and papers

APN+. 2004. *AIDS Discrimination in Asia*. Bangkok, Thailand: APN+.
<http://www.apnplus.org/webpage/Publications.html>.

APN+. 2004. APN+ Position Paper No. 1: “AIDS-Related Discrimination and Human Rights”; and APN+ Position Paper No. 2: “GIPA.” Bangkok, Thailand: APN+.

http://www.7sisters.org/resource_centre/common/APN%20Discrimination%20%20Human%20Rights%20Position%20Paper%20-%20Jan%20%27031.pdf and

http://www.gnpplus.net/component/option,com_docman/task,doc_view/gid,207/Itemid,53/.

De Bruyn, M. 2005. *HIV/AIDS and Reproductive Health: Sensitive and Neglected Issues. A Review of the Literature. Recommendations for Action*. Chapel Hill, NC: Ipas.

http://www.ipas.org/Publications/asset_upload_file268_2956.pdf.

Global Network of People Living with HIV (GNP+). 2007. *A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanisms (CCM)*. Amsterdam: GNP+. http://www.gnpplus.net/component/option,com_docman/task,cat_view/gid,76/Itemid,53/.

ICW. 2004. *Visibility, Voices, and Visions: A Call for Action from HIV-positive Women to Policy Makers*. London: ICW. <http://www.icw.org/publications>.

ICW. 2004 and 2007. “Vision Papers.” London: ICW. <http://www.icw.org/publications>.

ICW. 2006. “HIV Testing and the Rights of Women Living with HIV.” *AIDS Legal Network Newsletter*, September 2006: 27–28. <http://www.icw.org/files/ALQ%20Sept%202006%20-testing%20-.pdf>.

ICW/Global Coalition on Women and AIDS. 2006. “Fact Sheets.” London: ICW.

<http://www.icw.org/publications>.

International HIV/AIDS Alliance. 2003. “Positive Prevention: Prevention Strategies for People with HIV/AIDS.” Draft Background Paper. Brighton, UK: International HIV/AIDS Alliance.

<http://www.aidsalliance.org/sw9438.asp>.

International Planned Parenthood Federation (IPPF). 2007. “IPPF Charter on Sexual and Reproductive Rights.” London: IPPF.

<http://www.ippf.org/en/Resources/Statements/IPPF+Charter+on+Sexual+and+Reproductive+Rights.htm>.

IPPF/UNFPA/Young Positives. 2007. *Change, Choice, and Power: Young Women, Livelihoods, and HIV Prevention. Literature Review and Case Study Analysis*. London: IPPF.

<http://www.ippf.org/NR/rdonlyres/50CC6D5F-F254-4659-86CB-265F281FA625/0/ccp.pdf>

Ipas. 2006. “There’s Nothing You Could Do If Your Rights Were Being Violated: Monitoring Millennium Development Goals in Relation to HIV-positive Women’s Rights.” Chapel Hill, NC: Ipas.

http://www.ipas.org/Publications/asset_upload_file211_2896.pdf.

Paxton, S. 2005. *Steps to Empowerment: Challenges to the Greater Involvement of People Living with HIV in the Response to AIDS in Cambodia*. Washington, DC: POLICY Project/Constella Futures.

http://www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf.

Welbourn, A. 2006. “Sex, Life, and the Female Condom: Some Views of HIV-Positive Women.” *Reproductive Health Matters* 14(28): 1–9. <http://www.icw.org/files/articleRHM-AW.pdf>.

Note: All links in this resource list were valid at the time this guide was prepared. Websites change and thus these links might not remain valid in the future.



APN+ is the regional network of people living with HIV and AIDS that represents HIV positive individuals and groups in the Asia Pacific Region. It is an organization run, by and for people living with HIV and AIDS. APN+ works to advocate for the rights of HIV positive people including access to treatment, care and support, to fight stigma and discrimination, and is involved in prevention interventions.

Asia Pacific Network of PLHIV (APN+)

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