

Advocacy relating to the sexual and reproductive health and rights of people living with HIV

People living with HIV have been talking about sex and reproduction from the beginning of the epidemic. HIV and AIDS forced gay men to redefine their sexuality and incorporate condom use in order to protect themselves and their partners from HIV and other sexually transmitted infections (STIs). From North America to Australia, they successfully articulated “safer sex” messages into peer education campaigns. More recently, organizations of women living with HIV have broadened the discussion to include issues and choices related to reproduction, including contraception, fertility, pregnancy, termination, birthing, and breastfeeding.

Programs and policies, however, have been slower to address sexual and reproductive health and rights. Early in the epidemic the focus was on preventing HIV, particularly among “vulnerable groups” of people, sometimes without acknowledging that people with increased vulnerability to HIV are part of the general population with the same needs and desires as anyone else. In 1996, triple combination antiretroviral therapy was proven to be effective in reducing viral load and disease progression, and advocacy efforts, followed by programmes, began to focus on providing treatment.¹

The first global agreement to define reproductive rights was the Programme of Action developed at the 1994 International Conference on Population and Development (ICPD)². The declaration affirmed people's right to enjoy a safe and satisfying sex life and to decide freely on matters relating to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. The rights of people living with HIV are not specifically discussed in this document, nor in the Millennium Development Goals developed in 2000.

In 1999, the International Community of Women Living with HIV/AIDS (ICW) produced the "Positive Women's Survival Kit", which addressed HIV-positive women's reproductive and sexual choices for the first time. Shortly afterwards, ICW conducted qualitative research around HIV-positive women's experiences, particularly in relation to their reproductive and sexual health, with partners in Zimbabwe and Thailand. This participatory research and advocacy project, called “Voices and Choices,”³ was led by HIV-positive women and explored the impact of HIV on their sexual behaviour, well-being and reproductive rights.

In the Declaration of Commitment agreed at the 2001 United Nations General Assembly Special Session (UNGASS) on HIV/AIDS, governments committed to “enact, strengthen

¹ <http://gateway.nlm.nih.gov/MeetingAbstracts/102231737.html>;

<http://www.aidsconsortium.org.uk/publicationspages/croquer.htm>

² United Nations International Conference on Population and Development. September 1994.

<http://www.un.org/popin/icpd2.htm>

³ ICW. 2002. Positive women - Voices and choices - Zimbabwe; ICW. 2004. Positive women - Voices and choices - Thailand. <http://www.icw.org/icw/files/VoicesChoices.pdf>

or enforce as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and freedoms by all people living with HIV". This includes the right to sexual and reproductive health. In the UNGASS Declaration, while indicators to monitor progress refer to vulnerable groups, young people and high-risk groups, they do not specifically mention women and girls (who have particular sexual and reproductive health needs that are frequently overlooked by current programmes).⁴

People living with HIV have engaged in successful global activism, particularly around access to antiretroviral therapy. Advocates spoke out clearly and persistently for treatment access as a human rights issue. They also showed that treatment assists prevention efforts because people are more willing to undergo testing if treatment is available, and treatment lowers viral loads and decreases the likelihood of infecting others. These powerful arguments led to international efforts including the World Health Organization's "3 by 5" initiative, the United States' President's Emergency Plan for AIDS Relief (PEPFAR), and the Collaborative Fund for HIV Treatment Preparedness.

Global efforts to increase access to treatment have generally not addressed sexual and reproductive health, however. Some early work has occurred in this area. In 2006, EngenderHealth, in conjunction with Harvard University, ICW, Ipas and UNFPA, conducted an electronic forum on sexual and reproductive health issues⁵. EngenderHealth and UNFPA also conducted qualitative research among women living with HIV in Brazil, Ethiopia and Ukraine,⁶ which has informed an EngenderHealth/ICW training manual on sexual and reproductive health for women and girls⁷. In 2005, WHO, IPPF, UNAIDS and UNFPA produced a framework for priority linkages in sexual and reproductive health and HIV⁸. To move these efforts forward and realize the sexual and reproductive health and rights of people living with HIV, advocates will have to overcome a number of barriers.

For one, AIDS-related stigma is entrenched in society. Many health-care workers think an HIV-positive diagnosis should mean an end to sex, and fail to provide people living with HIV with appropriate information on sexual and reproductive health. Clients subsequently feel guilty when they engage in sexual relations and are reluctant to discuss sex with health workers, so they lose out on appropriate information and care. Stigma also stops many people diagnosed with HIV from becoming involved in HIV activism. Because it is women who usually carry the burden of responsibility for contraception and

⁴ ICW. 2006. A critical look at the UNGASS indicators. <http://www.icw.org/node/128>.

⁵ EngenderHealth/Harvard University/ICW/Ipas/UNFPA. 2006. Sexual and reproductive health of HIV positive women and adolescent girls: A dialogue on rights, policies and services - Global electronic forum report on results. http://www.engenderhealth.org/aids/pdfs/tech-library/hiv/electronic_forum.pdf

⁶ EngenderHealth / UNFPA. 2006. Sexual and reproductive health needs of women and adolescent girls living with HIV. Research report on qualitative findings from Brazil, Ethiopia and the Ukraine. http://www.unfpa.org/upload/lib_pub_file/619_filename_srh-of-hiv-positive-women.pdf

⁷ EngenderHealth. 2004. Reducing stigma and discrimination related to HIV/AIDS: A training manual. <http://www.engenderhealth.org/res/offc/hiv/stigma/index.html#stigma>.

⁸ WHO / IPPF / UNAIDS / UNFPA. 2005. Sexual and reproductive health and HIV/AIDS. A framework for priority linkages. <http://www.unfpa.org/publications/detail.cfm?ID=250&filterListType=1>

pregnancy, unequal power within relationships can also be a significant barrier to improving sexual and reproductive health and rights. Women may be reluctant to talk about sex and inhibited from speaking out about their needs.

Young people, ethnic minorities, migrants, refugees, sex workers, men who have sex with men, transgenders, prisoners, injecting drug users, people with disabilities and other key populations may be similarly disadvantaged due to their marginalization and a lack of respect for their rights. As a result, not only are members of these groups more vulnerable to HIV infection at the outset, they also face additional challenges to having their rights upheld and gaining access to quality health services. Furthermore, they may be reluctant to become involved in advocacy. And when they do, even within national people living with HIV networks, their voices are not necessarily heard.

Persistent poverty erodes people's health and their ability to advocate for their rights – even as ill health itself can lead to or exacerbate poverty. People with inadequate incomes generally must devote their energies to looking after themselves and their dependents. It is also often difficult to access appropriate health care, especially if the person lives far from a health clinic⁹. Looking after one's own health may take very low priority if one is struggling to feed one's children, and women are rarely remunerated for the care work they provide. Juggling these concerns, an HIV-positive person living in poverty is hard-pressed to find time and energy to engage in advocacy for her sexual and reproductive health and rights.

Attitudes based on moral judgments hamper people's access to information and health care. Men who have sex with men, women who have sex outside marriage and transgender may all face disapproval or denial of services from health workers. Religious opposition to extramarital and premarital sex, or to condom use, means that people may not be given the information and skills they need to enjoy sexual and reproductive health and minimize harm to themselves and others. Some religious leaders undermine the sexual and reproductive health and rights of people living with HIV: for example, some churches in Tanzania refuse to marry people who are HIV-positive.

Repressive laws can also impede advocacy efforts. For example, laws that criminalize non-disclosure of HIV status, same-sex relationships, sex work, or drug use not only make it more difficult for vulnerable people to access information and care, they also make people reluctant to get involved in people living with HIV groups or any HIV-related activism for fear of disclosure.

Finally, the separate, parallel national-level responses to sexual and reproductive health and HIV are mirrored to some extent within the advocacy community. Women's reproductive health discussions have largely happened without men. Sexual health issues relating to men who have sex with men, sex workers or drug users have been addressed

⁹ ICW. 2006. Mapping of experiences of access to care, treatment and support – KENYA.

<http://www.icw.org/files/Kenya%20ACTS%20mapping.doc>

ICW. 2006. Advocacy tool - access to care, treatment and support for women living with HIV and AIDS in Swaziland. <http://www.icw.org/files/ACTS%20-%20SZ%20-%20final%2005-06.doc>

in isolation. Women and men need to collaborate to realize the vision of sexual and reproductive rights for all. Groups of people living with HIV need to collaborate with groups of drug users, men who have sex with men, transgender persons, sex workers, migrants, ethnic minorities, refugees, and prisoners and develop common policy platforms.

Even within groups of people living with HIV, it is sometimes difficult to overlook differences and recognize a common agenda. For example, widows may find it challenging to work alongside sex workers. It is important to share experiences, overcome prejudice and realize common ground. At times there is no common agenda, and difference and diversity need to be recognised. Sex workers or gay men, for example, may need their own forum to ensure that their specific needs are met without prejudice from others.

This chapter will begin by outlining key advocacy issues and highlighting ways to move the agenda forward more effectively. It will then suggest concrete ways to improve the ability of networks of people living with HIV to advocate for sexual and reproductive health and rights, so that their efforts result in action.

I. The advocacy agenda

At the most general level, advocates must continue to press for greater political attention and commitment to sexual and reproductive health in order to combat HIV. To meet the practical sexual and reproductive health needs of people living with HIV, advocacy efforts can also focus around several specific issues, including sexuality, HIV counseling and confidentiality, contraception, abortion, pregnancy and birth, parent-to-child transmission of HIV, income, and violence.

Sex education and sexual health

All young people deserve high quality sexual health education. Sex education reduces vulnerability to STIs, including HIV. Young people who receive sex education before they become sexually active tend to initiate sex at a later age, engage in safer sexual practices, and be monogamous¹⁰. Young women need to learn how to be assertive during sexual negotiation, and young men need to understand the importance and benefits of sexual negotiation rather than sexual dominance. Yet many young people, particularly young women, men who have sex with men and transgender persons, are deprived of sex education and services. Because of age of consent laws, health workers may be reluctant to provide sexual health information and services to even to young people who are

¹⁰ Levy S, Perhats C, Weeks K, Handler A, Zhu C, Flay B. 1995. Impact of a School-Based AIDS Prevention Program on Risk and Protective Behavior for Newly Sexually Active Students. *J School Health*. 65 (4): 145-52; Main D, Iverson D, McGloin J, Banspach S, Collins J, Rugg D, Kolbe L. 1994. Preventing HIV Infection among Adolescents: Evaluation of a School-Based Education Program. *Prev Med*. 23: 409-17; Walter H, Vaughan R, Ragin D, Cohall A, Kasen S, Fullilove R. 1993. Prevalence and Correlates of AIDS-Risk Behaviors among Urban Minority High School Students. *Prev Med*. 22: 813-24.

already sexually active.

Young people who were born with HIV need special attention and appropriate opportunities to discuss issues around sexuality, including entering into and negotiating sexual relationships. All people living with HIV need non-judgmental information about how to enjoy safe, pleasurable sex lives. They also need to be informed about the dangers of certain sexual practices. They should also be encouraged to explore non penis-centered sexual behaviors, such as mutual masturbation and oral sex (although the latter still carries risk of STIs).

After an HIV diagnosis, many people are led to believe that continuing to have sex is irresponsible. They then feel guilty for having sex. So they avoid health-care services and do not receive adequate and appropriate information, treatment and care. Men in same-sex relationships who are diagnosed with HIV may also avoid health services because of fear of judgmental attitudes. Integration or linking of sexual health services, HIV services (including harm reduction programmes) and reproductive health services can help people living with HIV access a broader range of sexual and reproductive health care.

People living with HIV should advocate for sensitive, affordable, rapid, simple, routine screening for and diagnosing of STIs at all health-care centres. Because HIV-positive people are more vulnerable to STIs, male and female condoms need to be accessible and promoted as dual protection against STIs and pregnancy. HPV vaccines should be made available in high-prevalence areas to prevent cancer; these vaccines should be made freely and readily available both to girls and to boys. More research is also needed on sexual transmission of hepatitis C and on the links between syphilis and HIV co-infection.

Women living with HIV need to know that it is important to have annual cervical pap tests, because of their heightened risk of cervical cancer and HPV. Pap tests need to be made available as part of the routine monitoring of HIV-positive women's health. Treatment should be available for women with pre-cancer or invasive cancer of the cervix, including antiretroviral therapy, surgery, radiation and/or chemotherapy. Men and women living with HIV also need to be made aware of their heightened risk of anal cancer and need to be able to access treatment for cancer.

Good nutrition is also important for good sexual and reproductive health. Nutritional information and support is important for all people living with HIV and particularly important for mothers with limited incomes, as some HIV-positive women sell their antiretroviral drugs in order to get money to feed themselves and their children. The ways people living with HIV balance competing needs must be considered in policies and programmes related to sexual and reproductive health and rights, HIV treatment and food support.

Recent data indicates that circumcision can significantly reduce a man's risk of HIV infections. Countries should include people living with HIV groups in their plans to

implement circumcision programmes¹¹, and should ensure that programmes include the promotion of condoms, counselling, informed consent and continued messaging around safer sex strategies to ensure their maximum effectiveness. Programmes must also be set up in a manner that enables the evaluation of their impact on women and involves women in monitoring the outcomes of circumcision programmes. Circumcision should be offered to men on a voluntary basis and men living with HIV should not be denied circumcision if they want the procedure.

HIV counselling and confidentiality

HIV-positive people frequently report that their HIV test results were given to family members (particularly husbands and fathers) before they received the results themselves^{12,13}. No HIV testing should be carried out unless confidentiality is guaranteed, counselling is provided, people receive adequate information about HIV treatment options, antiretroviral treatment is available, and people are clearly informed that they have the choice not to test and that their choice will not have an adverse impact on their ability to access health-care services.

Group counseling, which is common in many countries, does not provide people with appropriate opportunities to ask sensitive questions. It is important to promote individual, confidential counseling. HIV-positive men and women are particularly effective counselors, and programmes should seek to train and employ people living with HIV in this area¹⁴.

HIV-positive people in discordant relationships, in particular, need help with disclosing their status to sexual partners. Counselling can focus on how to encourage a partner to test or how to negotiate continued condom use. Disclosure of HIV status can be very beneficial, both for people living with HIV and the wider community¹⁵, but it should never be forced or coerced. Public disclosure should not be considered unless the person has good support from peers or family, and their income and housing will not be endangered.

Special attention should be paid to the practice of testing women who are pregnant. With the scale-up of antiretroviral therapy, antenatal testing is increasingly used to identify women who are HIV-positive for preventing parent-to-child transmission and as an entry

¹¹ GNP+. 2007. Implementing Circumcision Programmes: Opportunities and concerns for people living with HIV. <http://www.gnpplus.net/content/view/1324/91/>

¹² Human Rights Watch. 2007. WHO/UNAIDS: Expanded testing guidelines should recognize reality. Human Rights News. <http://hrw.org/english/docs/2007/05/30/global16020.htm>

¹³ Asia Pacific Network of People living with HIV. 2004. AIDS discrimination in Asia. http://www.gnpplus.net/component/option,com_docman/task,cat_view/gid,43/dir,DESC/order,name/limit,5/limitstart,5/

¹⁴ Bell E, Mthembu P, O'Sullivan S, Moody K. 2007. Sexual and reproductive health services and HIV testing: Perspectives and experiences of women and men living with HIV and AIDS. *Reproductive Health Matters*. 15 (29 Supplement): 113-135. <http://www.icw.org/node/294>

¹⁵ Paxton S. 2002. The Paradox of Public HIV Disclosure. *AIDS Care* 14(4): 559-67.

point for treatment programmes. However, there is little focus on the often-critical need for immediate follow-up care and support. An HIV-positive diagnosis during pregnancy can be a tremendous strain on a woman. In addition to emotional distress, she may face discrimination from her partner and family including violence, disinheritance, or loss of housing or income. Testing sites need to engage both partners in couple counseling, which enables parents to weigh up the benefits and risks of preventing mother-to-child transmission, including ART resistance, results in increased uptake of condom use, and help to reduce subsequent discrimination and violence when the partner discovers the woman's HIV-positive status¹⁶.

Because many women do not utilize antenatal care, it is important that antenatal clinics do not become the primary way for women to get access to antiretroviral therapy and that voluntary counselling and testing is more widely available outside antenatal clinics¹⁷.

Contraception

There can be enormous pressure on women diagnosed as HIV-positive not to have children. In some places treatment access is tied to women agreeing to use contraceptives¹⁸. In one study¹⁹, 45% of women were told not to have any more children after their HIV diagnosis (only 18% of men were given the same advice, suggesting that health-care workers place responsibility for contraception on women).

But health systems often provide inadequate information or services to help couples avoid unintended pregnancy. In resource-poor settings, the two most commonly used contraceptives are the IUD and female sterilization (because of their cost-effectiveness). Both are safe for HIV-positive women, but neither protects a woman from STIs and other infections. Sometimes sterilization is coerced, for example, after a woman requests an abortion; in other instances, sterilization has been refused because the woman does not have her husband's consent²⁰.

Because many women have no choice in how and when they have sex, they need information on and access to forms of contraception that are compatible with their lifestyles. Women often do not know their full range of contraceptive options, including hormonal contraceptives (including emergency contraceptive pills), IUDs, injectables,

¹⁶ de Bruyn M, Paxton S. 2005. HIV testing of pregnant women: What is needed to protect positive women's needs and rights. *Sexual Health* 2: 143-151.

¹⁷ Holmes W. 2006. Challenges faced by HIV-positive mothers in the Asia-Pacific region. *HIV Matters: Discussions on the global pandemic*. 1 (1): 5-13.

¹⁸ ICW. 2006. Mapping of experiences of access to care, treatment and support – Namibia. <http://www.icw.org/files/Namibia%20ACTS%20mapping.doc>

¹⁹ Asia Pacific Network of People living with HIV. 2004. AIDS discrimination in Asia. http://www.gnplus.net/component/option,com_docman/task,cat_view/gid,43/dir,DESC/order,name/limit,5/limitstart,5/

²⁰ ICW. 2006. Advocacy tool - the sexual and reproductive rights and health of HIV positive women in South Africa. [http://www.icw.org/files/sexual and reproductive health and rightss%20South%20Africa%20-%202006.doc](http://www.icw.org/files/sexual%20and%20reproductive%20health%20and%20rightss%20South%20Africa%20-%202006.doc)

and implants.

Women who use hormonal contraceptives should be encouraged to use condoms as dual protection to prevent STIs. They should also be given appropriate advice about any drug interactions between antiretroviral therapy and hormonal contraceptives. Further research is needed to examine the interaction between various hormonal contraceptives, antiretroviral therapy and drugs used to treat common opportunistic infections.

Female condoms enable women to have greater control over contraception but they are still not ideal, as the man usually knows that the female condom is present. Nevertheless, social marketing of female condoms needs to be increased, as research indicates that they are very acceptable to many women who prefer them to male condoms²¹. Promotion of both male and female condoms to women needs to be sensitive to women's ability to negotiate their use with sexual partners, as well as to availability and cost.

Vaginal microbicides may in future offer women much greater autonomy in their contraceptive options. People living with HIV must be involved in clinical trial design from the beginning. Currently microbicide research focuses only on HIV-negative women in terms of efficacy. Also there are serious ethical concerns over what happens to people who become HIV-positive during microbicide trials, whether ARV-based microbicides will make women drug resistant, and about exclusion criteria for and confidentiality of information about trial participants. There is also a need to examine whether microbicides protect the partners of HIV-positive women from HIV infection and a need to conduct research on vaginal physiology and the mechanism by which HIV transmission from women to men occurs²².

Abortion

All HIV-positive pregnant women should have access to safe abortion²³. Doctors are often reluctant to provide abortions or post-abortion care to HIV-positive women for fear of HIV transmission to themselves during the procedures. All medical staff need to be made aware of universal precautions and health services need to provide resources to enable medical staff to practice them in all situations (since only a fraction of all the people infected with HIV know their status).

According to the World Health Organization²⁴, both medical and surgical abortions are safe for HIV-positive women. Medical abortion may have lower risk of infection;

²¹ 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>

²² ICW/GNP+/NAPWA (US)/Global Campaign for Microbicides. 2006. HIV positive women and microbicides. Advocates brief. <http://www.icw.org/node/177>

²³ Cook C, Dickens B. 2003. Human Rights Dynamics of Abortion Law Reform. *Human Rights Quarterly*. 25: 1–59. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=407400

²⁴ WHO/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. http://www.unfpa.org/upload/lib_pub_file/616_filename_srh_hiv-aids.pdf

however, health-care providers should not recommend medical abortion instead of the quicker vacuum aspiration procedures simply because they do not want to perform an invasive procedure for an HIV-positive woman. More research is needed into possible interactions between ARV and drugs used to medically terminate pregnancy²⁵, as well as the extent to which medical abortion may lower the risk of infection to women living with HIV.

HIV-positive women also need good quality post-abortion care. They need to be told that they are at heightened risk if they undergo an unsafe abortion because they are less likely to be able to resist infections or survive hemorrhaging.

While like all women, women living with HIV often have difficulty obtaining abortions, in other instances HIV-positive women are urged to terminate their pregnancies²⁶. Any termination of pregnancy must only occur with the voluntary, confidential and informed consent of the woman. Policies regarding informed consent in abortion, as in testing and sterilization, must ensure that women, and particularly young women and women from ethnic minorities, are making voluntary, autonomous, non-coerced and fully informed decisions.

Pregnancy and childbirth

Women diagnosed as HIV-positive have every right to become pregnant and should be supported in their decision. The risk of HIV infection to a newborn infant is very small, given the right services and antenatal and postnatal care.

Couples in which one or both partners is living with HIV who want to have children need information that is not currently often available to them. For example, people need to be told how to use antiretroviral therapy to lower their viral load to undetectable levels during conception and pregnancy, making the transmission of HIV very difficult. They need greater access to alternative conception strategies that may prevent transmission of the virus, including artificial insemination and in vitro fertilization (IVF), where it is available to the general public.

Because HIV illness can decrease fertility, people living with HIV may need particular

²⁵ de Bruyn M. Unwanted pregnancy and abortion: what is the situation for HIV-positive women today? Forthcoming in proceedings of International Conference on Actions to Strengthen Linkages between Sexual and Reproductive Health and HIV/AIDS, 4-8 February 2007, Mumbai, India; WHO. 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. http://www.who.int/reproductive-health/docs/srhwomen_hiv aids/text.pdf;

²⁶ Human Rights Watch. June 2004. A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic. <http://hrw.org/reports/2004/dr0704/>

²⁶ Human Rights Watch. March 2006. Rhetoric and Risk. Human Rights Abuses Impeding Ukraine's Fight against HIV/AIDS. <http://hrw.org/reports/2006/ukraine0306/>

assistance to increase their reproductive options. These may include IVF, fertility drugs and artificial insemination for biological reproduction. More flexible policies and options are also needed to enable HIV-positive people to adopt children more easily.

According to WHO, women who are on antiretroviral therapy should continue throughout pregnancy²⁷. Anecdotal evidence indicates that doctors in several countries stop treatment in HIV-positive women who become pregnant, believing that the drugs are harmful to the foetus. This is a dangerous practice. Advocacy efforts must support adherence to antiretroviral therapy during and after the first trimester of pregnancy.²⁸ Women who test positive for HIV during pregnancy should be offered antiretroviral therapy during pregnancy and be given understandable information so they can make choices about their options. No one should be pressured into starting antiretrovirals unless she gives full and informed consent. Also, programmes should provide ongoing access to treatment for the mother after the birth, if she is in need.

Judgmental attitudes toward injecting drug users should not interfere with pregnant women's access to antiretroviral therapy, especially since perceptions that drug users are not able to adhere to treatment have been proven incorrect²⁹. In addition, substitution therapy should be made available to all pregnant women who are opioid-dependent drug users, including methadone, buprenorphine or prescription heroin³⁰.

HIV-positive women are more likely than HIV-negative women to give birth to underweight babies and to give birth pre-term. They need adequate pre- and post-natal care, including help in reducing the risk of malaria and diagnosis and treatment of STIs, particularly syphilis, gonorrhoea and Chlamydia. Women need counselling to understand the value of condom use during pregnancy and couples need encouragement to use them.

There is no reason why most HIV-positive women cannot have normal births. The risks of elective Caesarian section must be stressed. Caesarian section are only recommended well before the onset of labour and no later than 38 weeks; it is only recommended if labour is likely to be prolonged or other obstetrics complications are anticipated.

²⁷ WHO. 2006. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants in resource-limited settings: Towards universal access: Recommendations for a public health approach.

<http://www.who.int/hiv/pub/guidelines/pmtctguidelines3.pdf>

²⁸ Although pregnant women should not commence an ARV regime including Efavirenz in the first trimester, pregnant women who are already on such a regime should continue with their regime because the risk to the unborn child due to an increased viral load in the mother if she stops medication is even greater. If pregnant women are on Efavirenz, WHO guidelines suggest substituting it with Nevirapine, if possible, with close monitoring. ARV drugs should only be withdrawn under specialist advice because of the danger of viral rebound.

²⁹ ARV4IDUs Coalition. 2004. ARV for injecting drug users: Key facts on HIV treatments efficacy. Satellite meeting "HIV treatment for drug users – a realistic goal". XV International AIDS Conference. Bangkok, Thailand, 15 July 2004.

http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/factarv_20040712/fact%20sheet_tx%20efficacy%20English.pdf

³⁰ GNP+/ICW. 2005. Position statement - Injecting drug users and access to HIV treatment.

http://www.gnpplus.net/component/option,com_docman/task,cat_view/gid,88/Itemid,53/

Preventing transmission of HIV to infants

International efforts have focused on ensuring that HIV-positive pregnant women receive antiretroviral prophylaxis to reduce the risk of transmission to their babies. Prevention of parent-to-child transmission is tremendously important; at the same time, however, testing all pregnant women in low-prevalence areas, particularly where confidentiality is not guaranteed and where the incidence of false positive results is higher, can result in enormous negative repercussions. In low-prevalence regions, advocates for reducing infant mortality should consider the implementation of more comprehensive strategies including, for example, the reduction of malaria infection.

In settings where it does make sense to expand testing and treatment of pregnant women, it is important to offer the treatment regime that will be of the greatest benefit to both mother and child. In many countries, including India, China and in most African countries, HIV-positive pregnant women are given Nevirapine as a one-off dose during pregnancy because it is inexpensive and easy to administer. This provides a 50% reduction in HIV transmission from mother to child. Because of the risk of the mother becoming resistant to Nevirapine and to increase efficacy, the WHO now recommends a more complex regimen involving Nevirapine, Zidovudine, and Lamivudine for both mother and baby that reduces transmission by 80%³¹. ARV prophylaxis administered to babies born to HIV-positive mothers not on treatment must be provided within two days of delivery, otherwise it is unlikely to have any benefit.

Parent-to-child transmission prevention programmes should also be linked to reproductive health programmes to help women living with HIV prevent unintended pregnancies in the future. Counselling is important in helping women and men to make active choices in child spacing, particularly in cultures where many children are encouraged. Reducing unintended pregnancy in women living with HIV by 16% will have the same impact on reducing the number of children born with HIV as current one-off Nevirapine programmes, and the result is less invasive and more sustainable³².

Most programmes to prevent transmission of HIV from mother to child during pregnancy focus on the health of the child. There is rarely a holistic approach that acknowledges the psycho-social support that the mother might need. Yet without factoring this in, medical efforts to prevent HIV transmission during pregnancy may be pointless - especially if the child is infected during breastfeeding.

WHO recommends that HIV-positive women avoid breastfeeding if replacement feeding is acceptable, feasible, affordable, sustainable and safe³³. For women in much of the

³¹ WHO. 2006. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants in resource-limited settings: Towards universal access: Recommendations for a public health approach. <http://www.who.int/hiv/pub/guidelines/pmtctguidelines3.pdf>

³² Holmes W. 2005. The bigger picture: primary prevention and prevention of unintended pregnancies among women living with HIV. UNFPA background paper. Abuja Global Forum on Prevention of Mother to Child Transmission.

³³ WHO HIV and Infant Feeding Technical Consultation Consensus Statement. Held on behalf of the Inter-

world it is rarely all of the above. Exclusive breastfeeding is recommended in resource-poor settings where substitutes may be too difficult to come by and where stigma is high, but it is difficult to maintain exclusive breastfeeding and to stop it abruptly. Mixed feeding, of solids with breastfeeding increases the likelihood of HIV transmission, because substitute food aggravates the immature stomach providing entry points for HIV from breast milk.

Messages of "don't breastfeed" are inadequate. In many societies women who do not breastfeed are stigmatized. More research is needed about the impact of HIV disclosure and infant feeding patterns³⁴. In situations where baby formula and/or clean water are not available, exclusive breastfeeding with abrupt weaning may be the optimal strategy for many mothers to ensure child survival. Women need to be given clear guidance on how to abruptly wean an infant. Expressing and heat-treating breast milk is a very effective way to kill HIV, and, where practical, may be useful during the period of abrupt weaning.

Women also need to be told that taking antiretroviral therapy and reducing viral load to undetectable levels greatly reduces the risk of HIV transmission via breastfeeding.

Income

Poverty increases vulnerability to HIV and HIV increases vulnerability to poverty. If parents do not have an adequate income to feed their children, the health of the whole family suffers. Women affected by HIV are more likely to be poor; and poverty results in poor access to health care. Unless women have economic independence they are generally unable to assert their rights and ensure optimal self-health care. Governments need to be training, mentoring and employing more women living with HIV in their national response. International NGOs need to investigate opportunities for scaling up of micro-financing options for women living with HIV and child-headed households, as well as training and employing more people living with HIV in the sector.

Violence

Violence increases women's vulnerability to HIV, and many anti-violence efforts focus on reducing this risk³⁵. Less attention has been paid to the violence experienced by women living with HIV. Violence, or the fear of violence, can prevent women from accessing health care³⁶. Violence and rape lower self-esteem, increase the risk of

agency Task Team (IATT) on Prevention of HIV Infections in Pregnant Women, Mothers and their Infants. Geneva, October 25-27, 2006

http://www.who.int/child-adolescent-health/publications/NUTRITION/consensus_statement.htm

³⁴ Holmes W. 2006. Challenges faced by HIV-positive mothers in the Asia-Pacific region. *HIV Matters: Discussions on the global pandemic*. 1 (1): 5-13.

³⁵ ICW . 2006. *Violence against women* Fact sheets. <http://www.icw.org/files/VAW-ICW%20fact%20sheet-06.doc>

³⁶ ICW. 2006. Advocacy tool - the sexual and reproductive rights and health of HIV positive women in South Africa. http://www.icw.org/files/sexual_and_reproductive_health_and_rightss%20South%20Africa%20-%2006.doc

contracting sexually transmissible infections, and can lead to unwanted pregnancy, spontaneous abortion and unsafe abortion. Married women, sex workers, men who have sex with men, transgender persons, mobile population and refugees are more vulnerable to sexual violence.

Advocates should press for the recognition of marital rape as a crime. In several countries, particularly in Africa, widow inheritance jeopardizes the sexual and reproductive health of women and puts women at increased risk of STIs.

II. Improving advocacy

This ambitious agenda, which will require changes in both the health care and legal systems, will require a concerted advocacy effort on the part of people living with HIV and their allies and champions. To make this possible, advocacy networks will need to be strengthened with new skills and collaborations. No single person or group can be expected to advocate around all the issues raised here. Each group will have to set priorities based on the needs of the people represented, and develop partnerships with organizations who have overlapping constituencies and concerns to ensure, collectively, that the full range of sexual and reproductive health issues is addressed.

Education and training

First and foremost, people diagnosed with HIV need education about their rights to sexual and reproductive health. Most people diagnosed as HIV-positive voluntarily and willingly take on the responsibility not to infect others. Yet many are not aware that they have any right to be treated with dignity and respect in return. Sympathetic local and international NGOs can provide opportunities for capacity building, particularly in self-esteem, assertiveness, negotiation, rights and health, and advocacy skills. They can support and promote the use of existing training modules³⁷ for health providers and adapt the modules for women living with HIV in different national and cultural contexts. Additional modules for men living with HIV and other vulnerable populations should be developed.

Networks of people living with HIV and international donors can work together to enhance the advocacy skills of people living with HIV. Women living with HIV in particular are under-represented and often lack confidence and experience within the HIV sector. Young women living with HIV who are interested and motivated to be involved in advocacy should be nurtured and mentored. International NGO support for intensive training workshops on sexual and reproductive health and rights for all HIV-positive people's groups is a sound investment. Collaboration between people living with HIV

³⁷ EngenderHealth/ICW. 2006. Sexual and reproductive health for HIV-positive women and adolescent girls – Manual for trainers and programme managers.
http://www.engenderhealth.org/aids/pdfs/tech-library/hiv/SRH_for_HIV_Positive_Women.pdf

networks and partners towards ensuring the sexual and reproductive health and rights of women and men living with HIV has been a mutually beneficial process to date.

For example, in 2003, ICW and the Burkina Faso-based Responsibility, Hope, Life Association organized a “Voices and Choices” workshop for HIV-positive women from Francophone Africa, focused on the sexual and reproductive rights and experiences of women living with HIV. ICW and the Policy Project have also paid particular attention to young women’s needs through “Young Women’s Dialogues” where women from Namibia, South Africa and Swaziland have come together to develop advocacy agendas related to their sexual and reproductive health, access to care, treatment and support, and the meaningful involvement of young HIV-positive women in decisions that affect their lives.³⁸

In 2004, IPPF and GNP+ collaborated to produce a booklet “Fulfilling fatherhood. Experiences from HIV positive fathers”³⁹, however, on the whole, men are missing from the advocacy picture and programmes lack specific focus on men.

GNP+ has also been working with ICW, IPPF and UNAIDS to develop and pilot the people living with HIV Stigma Index, a tool to measure the levels of AIDS-related stigma experienced by people living with HIV. The tool can be used in a variety of settings as a vehicle for advocating to reduce HIV-related stigma, but it can also be usefully adapted to help in advocating for sexual and reproductive health and rights, as well.

Tired of being approached by researchers but never seeing the results, HIV-positive women in Lesotho and Swaziland devised a tool that they could use with other HIV-positive women to monitor access to care, treatment and support, sexual and reproductive health and rights, and violence against women⁴⁰. The tool provides a useful framework for bringing diverse groups together – HIV-positive women, health providers and government officials - helping the latter two groups to think critically about the impact of their actions on HIV-positive women, and providing a valuable opportunity to reduce the isolation faced by women living with HIV.

In a two-year project led by Ipas, ICW helped develop a monitoring tool to examine benchmarks related to three of the MDGs relevant to women’s reproductive health. They tested and refined the tool through pilot projects in Botswana, Lesotho, Namibia and Swaziland; other NGOs and associations of people living with HIV tested the benchmarks in Argentina, Kenya, Mexico, Nigeria, Peru, Poland and South Africa⁴¹.

³⁸ ICW. 2004. Young Women’s Dialogue, South Africa. <http://www.icw.org/recent-activities>

³⁹ GNP+/IPPF. 2005. Fulfilling fatherhood. Experiences from HIV positive fathers http://www.gnpplus.net/index.php?option=com_search&Itemid=5&searchword=Fulfilling+datherhoo&submit=Search&searchphrase=any&ordering=newest

⁴⁰ ICW, in collaboration with Support for the International Partnership against AIDS in Africa. 2005. Updated 2006. [Positive Women Measuring Change](http://www.icw.org/publications). <http://www.icw.org/publications>

⁴¹ de Bruyn M. 2006. *Fulfilling reproductive rights for women affected by HIV/AIDS. A tool for monitoring progress toward three Millennium Development Goals*. Updated version. Chapel Hill, NC, Ipas. http://www.ipas.org/publications/en/MDGHIV_E06_en.pdf;

de Bruyn M. 2006. “There’s nothing you could do if your rights were being violated.” Monitoring

Harnessing the unique expertise of people living with HIV

Women and men living with HIV can make important contributions to the HIV response. They can play an important role in positive prevention and in educating their peers and the public about the benefits of antiretroviral therapy, thus encouraging more people to come forward for HIV testing. Involving women and men living with HIV also has a significant impact on changing attitudes to HIV and reducing HIV-related stigma, but they have been underutilized in the response⁴².

The Paris AIDS Summit Declaration (1994), signed by 42 countries, acknowledged the essential role that people living with HIV have to play in the design and implementation of HIV and AIDS policies and programmes; this is known as the GIPA Principle. The United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS⁴³ promotes the involvement of people living with HIV/AIDS, young people, and civil society actors in the design, planning, implementation and evaluation of HIV and AIDS programmes.

A pre-requisite for country proposals submitted to the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria is that people living with HIV are represented in the Country Coordinating Mechanisms (CCMs). GNP+ developed a tool to guide people living with HIV in relation to their involvement in CCMs⁴⁴. In some countries it has been difficult for the HIV-positive representative to get their voice heard and their concerns addressed.

It is important to encourage, train and pay HIV-positive people as educators, counsellors, researchers, programme designers and policy-makers. They can be trained to take on these roles and be employed by governments and NGOs and thereby gain sustainable livelihoods and at the same time contribute to a more successful HIV response.

It is important to increase the capacity of people living with HIV networks and not simply “cherry pick” the most competent and/or educated HIV-positive people. It is also necessary to give people living with HIV networks adequate notice before meetings are held. Often people living with HIV are the last to be notified of important meetings and have little or no time to consult with their peers about the issues to be decided at the meeting, and sometimes they do not attend because of the short notice given.

Millennium Development Goals in relation to HIV-positive women's rights. Chapel Hill, NC, Ipas.
http://www.ipas.org/publications/en/MDGMON_E06_en.pdf

⁴² Paxton S. 2002. The Impact of Utilizing HIV-Positive Speakers in AIDS Education. *AIDS Education and Prevention* 14.(4): 282-94; Takai A, Wongkhomthong S, Akabayashi A, Kai I, Ohi G, Naka K.1998.

Correlation between history of contact with people living with HIV/AIDS (PWAs) and tolerant attitudes toward HIV/AIDS and PWAs in rural Thailand. *International Journal of STD and AIDS*. 9.(8):.482-484.

⁴³ United Nations General Assembly Special Session Declaration of Commitment on HIV and AIDS. 27 June 2001. <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

⁴⁴ Global Network of People living with HIV (GNP+). 2005. Challenging, changing and mobilizing: A guide to people living with HIV involvement in Country Coordinating Mechanisms.
<http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf>

The integration of HIV and sexual and reproductive health provides an opportunity to assess and bridge gaps in services and to review budgets and funding and maximise resources, including human resources. When health departments develop policies for service integration, they need to involve HIV-positive people on decision-making committees so that they can help to inform departments about the most efficient ways to deliver comprehensive care. Integration can also contribute to reducing HIV-related stigma and stigma related to other contentious and sensitive issues such as same-sex relationships, drug use, sex work, unwanted pregnancies and abortion and ensuring patient confidentiality.

Strengthening Networks

International NGOs must ensure the continued development of networks and self-help groups of people living with HIV. Peer support groups are hubs of HIV activism. They provide opportunities for information exchange and sharing of experiences and are invaluable sources of emotional support. It can be constructive to support separate groups with specific interests - for example, groups especially for women, men who have sex with men, transgenders, sex workers, drug users, migrants, refugees, and prisoners. Networks of people living with HIV can encourage support groups to learn more about, and advocate for, sexual and reproductive health and rights.

Policies that address representation of HIV-positive people must also include strategies to ensure that the people who are representing the community have the skills to do so. Women and men living with HIV need training so that they can have meaningful involvement and participation on all decision-making bodies relevant to their lives, such as UN bodies, Global Fund bodies, National AIDS bodies, NGOs, health departments or education curriculum development units. They need to be able to share experiences and feed material into key decision-making at local, national, regional and international levels. They may need mentoring by international NGO staff on what to expect and how best to respond.

Women in particular are rarely involved in policy-making unless it is specifically about women's issues. When they are involved, their work often goes unrecognized and they have difficulty gaining access to or being taken seriously by policymakers. Wherever a representative position is held by a man, it is important to ensure a woman is engaged as an alternative representative and is provided with skills and information so that she can take on the position of responsibility. Women living with HIV also need opportunities to build their self-esteem before they can begin to advocate to and negotiate with policymakers.

National organizations of people living with HIV must be encouraged to undertake strong organizational development, ensure good governance and train representatives who can liaise well with government officials. NGOs can link with organizations of people living with HIV and help to mentor HIV-positive individuals for roles in the public health sector. Young people, particularly women, must be trained and mentored to become leaders, so that they can sit on decision-making bodies and meaningfully participate in

policy and programme design, implementation and monitoring and evaluation. At the same time these ‘representatives’ must be supported to remain accountable to the communities they represent. Only by involving HIV-positive people at this level will effective change happen.

Mentoring Positive Networks

Igat Hope is the national organization for people living with HIV in Papua New Guinea, a country with high rates of HIV infection. When Igat Hope first formed, members had no experience in how to run a network and were not represented on any national committees. Recognizing the need to enhance the skills of their neighbouring peers, the National Association of People living with HIV (NAPWA), Australia, developed a partnership with Igat Hope. They managed to obtain funds for two people living with HIV from NAPWA to visit Igat Hope several times over a two-year period and provide organizational development training. Igat Hope now has a fully functioning Board, a strong governance structure, and a paid full-time coordinator, and is increasingly asked to be involved in HIV-related policy decisions.

WHO has recommended that 50% of a nation’s health-care budget goes into building infrastructure, including the training of health care workers. This should include sexual and reproductive health and rights training for HIV service providers, HIV specialists, and in all medical training courses. Health-care provider training should utilize trained women and men living with HIV who are willing and able to be open about their HIV status. This is an opportunity to advocate to engage women and men living with HIV in health care provider training and employ them within the sector as paid workers on the health care team. Task shifting has shown to be useful in freeing up time of health care workers to engage in more challenging work in HIV patient management while engaging the expertise of people living with HIV to assist with peer sexuality counselling, adherence monitoring and peer support.

There is no doubt that a heavy investment in capacity building of people living with HIV and of health care workers is resource intensive. Funds will need to be committed for this. However, by focusing efforts on training, of both people living with HIV and health care workers, advocacy can be sustainable over the long term.

Addressing stigma and discrimination

People living with HIV will not get involved in training or in advocacy work if they fear that they may face discrimination and human rights abuse as a consequence. Strategies for reducing HIV-related stigma and discrimination and opening discussion within communities about HIV, sex, and drug use are essential to all efforts to reduce rates of HIV infection and improve the sexual and reproductive health of people living with HIV. This is challenging in many cultures, yet all cultures change according to the needs of the community.

HIV-positive speakers significantly change young people's attitudes to HIV⁴⁵ and can be powerful community educators, helping to reduce fear and break down stigma. Ministries of Education should be encouraged to engage young men and women living with HIV, who openly disclose their status, within HIV education programmes in schools. The private sector can be brought into supporting HIV education for in and out-of-school youth as well as in the workplace.

Managing knowledge and forming partnerships

Advocacy's greatest ally is evidence. People living with HIV need to develop more efficient ways to share, analyse and utilize information. A high-quality, respected body of evidence can back up advocacy arguments and enable groups of people living with HIV to counter arguments from decision-makers who attempt to justify poor policies, such as "opt-out" testing or routine circumcision. More effective and accountable mechanisms are needed to bring the diverse voices of people living with HIV from the community level to national, regional and international levels without creating an additional burden of reporting. This can be achieved by linking with established research institutions to get people living with HIV-related issues onto the agenda of these institutions and by strengthening local people living with HIV networks so they are capable of systematically collecting data.

Developing strategic partnerships can help to strengthen the advocacy efforts of people living with HIV networks. People living with HIV need to be clear on their own agenda so that they are not subsumed into the agenda of other organizations. However, they should also be willing to address issues of concern to their coalition partners' work (e.g., sex worker rights). Once an advocacy issue is identified, data should be collected and decisions made about who are the key people in power. It will then be clear how to frame messages, and to whom, to effect change. It is important to identify and target sympathetic leaders within the most relevant organizations or departments. The network of people living with HIV can then, for example, organize a small delegation to discuss the issues with them and lobby for change.

HIV-positive women effectively lobbying MPs to address their needs

ICW, Centre for the Study of AIDS (CSA), International Center for Research on Women (ICRW) and Realizing Rights: the Ethical Globalisation Initiative (EGI) are working with parliamentarians as part of a consortium to improve women's access to health care in Botswana, Namibia, Kenya and Tanzania. The aim of the Parliamentarians for Women's Health (PWH) project is to improve parliamentarians' understanding of the health issues that women, especially HIV-positive women, face, including barriers to access to treatment and sexual and reproductive health facilities.

⁴⁵ Paxton S. 2002. The Impact of Utilizing HIV-Positive Speakers in AIDS Education. *AIDS Education and Prevention* 14.(4): 282-94

In Namibia the evidence-gathering component of the project served as a springboard for bringing diverse groups together such as HIV-positive women, health providers and government officials. The results of the project's assessment were shared by the project officers at a round table discussion with parliamentarians and service providers at a women's health workshop held in October 2006. The Deputy Home Affairs Minister, Teopolina Mushelenga, who was present, backed the assessment findings by confirming that gender inequality and disparities, and socioeconomic issues such as poverty, social exclusion, unemployment and poor housing are some of the problems having an impact on women's rights to health. This was an important demonstration of support for all women in Namibia.

The ICW project officer, Jennifer Gatsi, has set up a 13 member Women's Khomas Health Committee, made up of mainly HIV-positive young women. The project in Namibia aims to empower 13 women based in Windhoek and 4 female Members of Parliament through a series of trainings which includes sexual reproductive health and rights. The 13 women will then be linked with MPs and with a committee of 26 women to be selected later in 2007 from the 13 regions (2 women - 1 older and 1 young woman - from each region). Committee members will be trained by the 13 women so that they can spread information to women across Namibia including to women in the villages. All the women will also be involved in monitoring services and talking to community members so that they can bring important issues to policy-makers. The project aims to ensure that HIV-positive women are meaningfully involved in decision-making, including national policies, that impact on their lives. Through training parliamentarians they hope to build the capacity of those in positions of power to engage with HIV-positive people in ways that are equitable, respectful, and productive for all involved.

http://www.icw.org/files/Listening%20to%20HIV%20positive%20Women_Parliamentarians%20for%20Womens%20Health.pdf

Networks of people living with HIV can link with specific issue-based groups, including harm reduction networks, organizations representing sex workers, men who have sex with men, transgender persons, migrants, prisoners, refugees and ethnic minorities and/or human rights bodies, to maximize their effect. Advocates can also become more proactive in getting involved in other organizations and government sectors, for example, local health and education departments, migrant organizations and labor organizations.

Stronger links are needed between the local, national, regional and international responses to HIV. People living with HIV have to use all possible channels to communicate successes and challenges to colleagues focused on the sexual and reproductive health of people living with HIV as well as to broader civil society. Organizations of people living with HIV also need to utilize the media wherever possible.

Monitoring legal responses to sexual and reproductive health and rights

Women and men living with HIV are entitled to enjoy the same rights as other people, including the rights to privacy, to health, to found a family, to live free from violence, to enjoy the benefits of scientific progress, to work, to education, to be free from inhuman or degrading treatment, and to shelter. These rights are embedded in United Nations declarations and treaties such as the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), the Convention on the Rights of the Child (CRC), the International Covenant on Civil and Political Rights, and the International Covenant on Cultural, Economic and Social Rights.

These treaties can be used as advocacy tools. National laws in some countries reflect the international agreements that those countries have made. However, this is not always the case, and even where it is, implementation of the law is often weak. Activists need to make themselves aware of what international treaties their government has ratified and what national laws can be used to uphold the rights of people living with HIV.

Key players, including women and men living with HIV, international NGOs, and UN agencies, must work with legal experts and human rights activists to ensure that civil society “shadow reports” on the monitoring of sexual and reproductive rights are delivered to the Human Rights Treaty Monitoring Committees. These Committees review periodic reports from governments on how they are complying with their human rights commitments and the system of shadow reports enables people living with HIV to provide supplementary information on possible violations of rights guaranteed in treaties such as CEDAW and the CRC. People living with HIV can also report rights violations and discrimination to national Human Rights Commission, if such a body exists in their country.

People living with HIV can work together with international NGOs and legal and human rights experts to convince governments that acknowledging and legalizing same sex relations, sex work and harm reduction programmes are integral to complying with international human rights norms, as well as important elements of a successful response to HIV.

Migrant worker receiving countries must be pressured to ratify the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families⁴⁶, remove mandatory testing of migrant workers and stop entry restrictions to countries based on HIV status. It is important to advocate for the right to health of everybody in the country, regardless of residency status.

Documenting discrimination

In the first project to document the nature and extent of AIDS-related discrimination, the Asia Pacific Network of People living with HIV (APN+) collected data from more than

⁴⁶ United Nations. 18 December 1990. International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. http://www.unhcr.ch/html/menu3/b/m_mwctoc.htm

760 people living with HIV in India, Indonesia, the Philippines and Thailand.

The major findings include:

- most discrimination happens in the health sector
- most people diagnosed with HIV face discrimination in the health sector
- people who are coerced into testing face significantly more discrimination than people who choose voluntarily to test
- women face significantly more discrimination than men do within the community.

These findings are being used in advocacy efforts internationally to raise awareness of human rights violations of people living with HIV. In addition, the process of training positive people to collect data was empowering. It made them realize their rights, and many have become actively involved in national advocacy efforts.

http://www.apnplus.org/home/index.php?option=com_docman&task=cat_view&gid=13&Itemid=26

Organizations of people living with HIV can work with their partners to monitor and report on treaty implementation and on violations of rights. Another important opportunity will be the next review of the UNGASS Declaration, which will be in 2008. People living with HIV and partners can gather information on the level of implementation of the declaration within their country in preparation for this review. International donors can support these efforts. Several tools are available to conduct this monitoring, including:

- ICW monitoring tool on access to care, treatment and support, violence against women and sexual and reproductive health and rights⁴⁷
- Ipas monitoring tool on sexual and reproductive health and rights in relation to MDGs⁴⁸
- GNP+, ICW, IPPF, UNAIDS PLHIV Index to measure stigma and discrimination
- APN+ peer-research model⁴⁹
- GIPA report card

Women and men living with HIV should be trained and involved in these monitoring processes. The involvement of the communities most affected by HIV will result in ownership. Peer-based research by people living with HIV indicates that those involved in research design and data collection become more aware of issues and more empowered to act when their rights or the rights of their peers are violated.

⁴⁷ 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. <http://www.icw.org/files/monitoringchangetool-designed.doc>

⁴⁸ de Bruyn M. 2006. Fulfilling reproductive rights for women affected by HIV/AIDS. A tool for monitoring progress toward three Millennium Development Goals. Updated version. Chapel Hill, NC, Ipas; http://www.ipas.org/publications/en/MDGHIV_E06_en.pdf

⁴⁹ APN+. 2004. AIDS Discrimination in Asia.

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III. Conclusion

People living with HIV and their partners and allies will be the ones to take the lead in pressing for policies and programs that take account of the fact that most HIV-positive people are sexually active and require sexual and reproductive health care. An HIV diagnosis does not take away a person's right to have sex or bear children. It does mean that people may need additional or different information and services to protect their sexual and reproductive health.

It is important to continue to strengthen the capacity of networks of people living with HIV so their voices can inform policies and programs. This includes general organizational development and advocacy skills, as well as specific information and training around sexual and reproductive health. Simultaneously, advocacy efforts should focus on specific policies and services, including sex education, HIV testing and counseling, contraception, abortion, pregnancy and childbirth, breastfeeding, poverty, and violence.

At all times, advocates must stress the meaningful involvement of people living with HIV – including women and members of marginalized groups – in the development, implementation and monitoring of laws and programs. Ultimately, following the lead of those who are most affected will enable decision-makers to respond with effective sexual and reproductive health services. And taking the lead in defining and evaluating policies and practice will ensure that people living with HIV are aware of their rights and empowered to act when these rights are violated.

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