Advocacy to Address the Sexual and Reproductive Rights of Women Living with HIV at the Country Level in the South and the North

Session held on 24 July 2012 at the XIX International AIDS Conference

This report provides coverage of presentations and discussions held at this session of the 2012 AIDS Conference. The session was not part of the official program but held in the Global Village with about 90 delegates attending. The organizations involved in the session were Ipas, CHANGE, Namibian Women's Health Network, ICW Malawi and The Women’s Collective.

The speakers were: Jennifer Gatsi Mallet of Namibian Women’s Health Network, Jamila Taylor of Ipas, Marie Khudzani Banda of ICW Malawi, Serra Sippel of CHANGE and Toni Holness of The Women’s Collective. Maria de Bruyn of Ipas chaired the session and prepared the final report. Our thanks to Brynn Kolada, CHANGE intern, for taking notes during the session!

PRESENTATIONS

Unwanted pregnancy and unsafe abortion in Namibia: testimonies from women affected by HIV – Jennifer Gatsi Mallet, Namibian Women’s Health Network

NWHN’s work on sexual and reproductive health and rights (SRHR) over the past five years has included:

- Capacity-building for youth and adults on gender, violence, contraception, unwanted pregnancy, unsafe abortion and reproductive rights
- Advocacy on access to contraception, emergency contraception, post-exposure prophylaxis
- Establishment of health ethics committees comprising representatives of staff, community leaders and clients at two urban clinics; these committees address complaints about patient treatment and highlight instances of good care. This pilot
The project was adopted by the government as a model program in January 2012, which the government intends to replicate in other clinics as a way of improving client care.

- Youth Economic Empowerment Program, incorporating components of SRHR into the educational component

In addition to work on coerced sterilization of women living with HIV, NWHN has also undertaken awareness-raising, education and advocacy on the issues of unwanted pregnancy, unsafe abortion and child abandonment:

- Abortion is legally permitted for danger to a woman’s life, danger to her physical and mental health, in cases of rape and incest, and cases of fetal malformation
- Legal abortions are scarcely performed; no government information is given to communities or health-care providers about circumstances in which legal abortion is permitted
- Yet in 2009, the Minister of Health stated: “about one third of the [maternal] deaths were due to septic and illegally-induced abortion most likely unsafely performed somewhere…. Fifty-nine per cent of the women dying of abortion related complications were under the age of 25.”
- Emergency contraception was only provided at 29% of surveyed health facilities offering family-planning services in 2009.
- There is a high incidence of “baby dumping”, in which newborn infants are abandoned by women who cannot care for them.

In 2011, NWHN carried out a project with support from Ipas to collect information about and testimonies from women about their experiences with unsafe abortion. Private interviews with written informed consent resulted in publication of 19 anonymous stories from three regions about unsafe abortions among girls and women who were aged 12-24 years at the time of the unwanted pregnancy. Some of those women died; the testimonies were given by friends and relatives in these cases [http://www.salamandertrust.net/resources/NWHNstorybooklet2011.pdf].

There was a public launch of the booklet of testimonies on 3 August 2011, which 50 people attended, including partners, stakeholders, media, government staff and civil society representatives. The launch was given media coverage on TV, in the printed press and via the Internet. NWHN presented a letter to the Minister of Health in which they asked the Ministry to request a strategic assessment on contraception, unwanted pregnancies, abortion and child abandonment with assistance from WHO. They want the government to conduct the research to determine the real situation within the country around unwanted pregnancies and unsafe abortion.
In a separate meeting, the Deputy Minister of Health promised follow-up on the issue. This did not happen and a reminder was given to the Minister of Health. NWHN is now raising the issue of unsafe abortion through its membership in a national technical committee on SRH, asking that the Ministry make information on the legal indications for abortion available to health-care providers and community members and calling for a review of the current abortion law to identify needed amendments.

**U.S. advocacy efforts to secure reinterpretation of the Helms Amendment – Jamila Taylor, Ipas**

The Helms Amendment is a Congressional provision regarding U.S. foreign assistance funding that was adopted by the US Congress in 1973. It states that U.S. foreign assistance funds cannot be used to “pay for the performance of abortions as a method of family planning or to motivate or coerce any person to practice abortion.”

The term “as a method of family planning” is not defined by the Helms Amendment; this is important because abortions performed in cases of rape and incest, and to protect a woman’s health and life are not provided as methods of family planning. The term “motivate” in the Helms Amendment was further clarified in 1994 through the Leahy Amendment; it should not be construed to preclude information and counseling on all pregnancy-related options in the context of local law. This means that abortion counseling, information and referral for services is permissible if abortion is legal in the country concerned.

The Helms Amendment is not the same as the “global gag rule” (Mexico City Policy), which was instituted under the last Bush presidency and then rescinded by President Obama. This rule applied restrictions to family planning funding only, stating that no U.S. money could go to family-planning groups that also provided abortion-related services, even using their own money.

Ipas conducted three separate research projects between 2008 and 2011 examining how the US government was implementing the Helms Amendment [e.g., http://www.ipas.org/-/media/Files/Ipas%20Publications/HELM5NPE10.ashx]. Over 200 interviews were conducted with RH organizations, health care providers, government officials, multilateral agencies, bilateral donors, and opinion leaders based in eight African countries and the U.S. During the research, Ipas worked in close consultation with USAID grantees and advocacy groups headquartered in Washington, DC (including the Guttmacher Institute, Center for Reproductive Rights, Marie Stopes International, Pathfinder International, CHANGE, and others).

The research revealed the impact of the Helms Amendment on U.S. Global AIDS Programs:
- Service providers and field staff find it hard to provide women living with HIV with unbiased RH options
They have no clear understanding of whether or not referrals and counseling for abortion are permissible.

They understand the Helms Amendment to be a complete ban on provision of all abortion-related care and services.

This means that groups receiving US funding believe that they cannot provide counseling on abortion to women living with HIV. Much of the U.S. funds for interventions addressing gender-based violence, for example, are funneled through OGAC/U.S. Global AIDS Program. Currently, none of that money is being used to provide abortions in any case and that has vast implications for women accessing U.S.-funded gender-based violence programs who find themselves pregnant as a result of sexual assault.

The misunderstandings could also be attributed to residual effects of the global gag rule. Service providers and field staff have inadequate knowledge of the policy change; there could also be a “chilling effect”, that is, a fear of providing services only to have the policy change again if the U.S. president/administration changes in the future. The cross-cutting consequences of the Helms Amendment include: denial of information, counseling, and services (even when legal); confusion among grantees; excessive censorship; increased stigma and injustice for women; and increased injuries and deaths due to unsafe abortions.

**Recommendations emanating from the research:**

- U.S. government agencies (USAID, PRM and PEPFAR) should include abortion services in cases of rape, incest and danger to a woman’s life due to pregnancy within their global health programs; doing so in the funded gender-based violence programs could be a first step.
- The U.S. government should issue clear guidance on permissible activities and compliance, reiterating what is stated in the Leahy Amendment.
- Advocates should stay informed about policy and procedural changes and work with key stakeholders (health ministries, civil society groups, health-care providers, etc.) to ensure the full SRHR of women living with HIV.

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**Awareness-raising and education among community women in Malawi – Marie Khudzani Banda, ICW Malawi**

In Malawi, there is a high rate of unintended pregnancies due to the limited availability of family planning services and contraceptives. Many of these pregnancies are among young girls and they lead to abortions (most unsafe as abortion is currently only permitted legally to save a woman’s life), infant deaths, and pregnancy-related deaths which could be prevented.

In 2007, I participated in a two-week international training-of-trainers workshop in Namibia on gender, HIV and reproductive rights organized by Ipas. After that, I facilitated similar
training for ICW members with support from Ipas and from 2008-2011, we held sessions in communities to inform and educate women living with HIV on issues related to contraception, pregnancy, and abortion. Because abortion is largely illegal, many women did not realize that safe abortion is possible.

These sessions, in different parts of the country including Lilongwe, Blantyre and Mzuzu, also included women living with disabilities. Partners in this work have included the Ministry of Health, Commission on Human Rights, National Nurses Council and Ipas.

In 2010, ICW became a member of COPUA, the Coalition to Prevent Unsafe Abortion in Malawi. One of our members participates in committees and we attend events to which we are invited. We also collected testimonies from women in communities about their experiences with unsafe abortion [http://www.salamandertrust.net/resources/ICWMalawibookletfinal20October2009.pdf]. The booklet was disseminated among policy-makers and civil society groups. I was also invited to speak at a side event during the UN Commission on the Status of Women.

Our sessions have shown that women living with HIV face a number of challenges to their reproductive health:

- Women have unwanted pregnancies due to low availability of family-planning services and contraceptives.
- Many of these unwanted pregnancies occur among younger women.
- These unintended pregnancies lead to abortions (most unsafe), infant deaths and pregnancy-related deaths which could be prevented.
- Women suffer long-term injuries (for example, a young woman who lost her uterus at age 14 years).
- Abortion is a sensitive topic so it is not discussed openly; however, women DO want to talk about it when they feel there is a safe space to do so.

Our members have stated clearly that they wish to see the abortion law liberalized; their recommendations include:

- Government should take urgent action to harmonize the law on abortion with its international treaty agreements to ensure protection of its vulnerable citizens
- Enact and/or implement policies and legal frameworks to reduce the incidence of unwanted pregnancies and unsafe abortions
- Train service providers in the provision of comprehensive safe abortion care services as allowed by national law.
- Educate communities on available safe abortion services as allowed by national law and on post-abortion care
- Continue community sensitization through media, TV, Posters
• Address the lack of essential supplies and equipment such as MVA, cancer-screening technologies, etc.

The women in our community sessions also asked us to continue our information and education efforts, which we are still doing. We welcome the efforts of journalists and other CSOs who are working to sensitize community members and policy-makers on the need to reform the law. We also hope that the government will address the lack of essential supplies needed to address our reproductive health issues.

“HIV-positive mothers who become pregnant are making a responsible choice for the children they already have if they end the new pregnancy early and in a safe way.”

Efforts to ensure that the US Global AIDS Program (PEPFAR) supports meaningful integration of HIV/AIDS and reproductive health care – Serra Sippel, CHANGE

I’m delighted to be included in this session, but I have to start by saying I really don’t see why we’re here at all. In my opinion we have nothing to discuss. As Hillary Clinton stated yesterday morning: “Every woman should be able to decide when and whether to have children. This is true whether she is HIV-positive or not.”

Women living with HIV have all the rights that should be available to every human being on earth. They have – or should have -- the right to freely and responsibly determine the number and spacing of their children. They have – or should have -- the right to control who they have sexual relations with, and when, and to protect themselves and their partners from sexually transmitted infections, including HIV, as well as unintended pregnancy. They also have – or should have -- the rights of access to education, to health care, to free speech and association, to loans and credit, to property and inheritance, to political involvement, to employment, to religion, or no religion, and so on.

All women should have all rights, and men, too. I’m sure we can agree on that. Human rights are universal and not subject to quibbles of gender or culture or ideology -- or health status either.

My organization, CHANGE, is based in Washington DC, where we advocate for the sexual and reproductive health and rights of women and girls globally, through the development and implementation of U.S. policies. Three years ago, when CHANGE visited Botswana to look at PEPFAR and integration of HIV and SRHR, a woman living with HIV brought me to a
U.S.-funded HIV/AIDS program there so that I could understand how HIV and reproductive health are linked for women living with HIV, but also to see the challenges women living with HIV face in accessing family planning.

While the PEPFAR-funded program helped women living with HIV access treatment so that they could give birth to infants free of HIV, supported a peer mothers’ program and provided maternal health services, the women were not given counseling, information or supplies to prevent future pregnancies. We were told it is an HIV/AIDS program, and that for family planning matters, the women should visit a government clinic or hospital. This situation led me to several points I would like to make here.

**Point 1: HIV and RH are linked**

HIV and reproductive health are intricately linked in a woman’s life, and linking voluntary family planning services and HIV prevention and treatment programs improves access to quality health services. Yet, siloed funding and siloed programs – such as the one I visited in Botswana – de-link them, and as a result, women are denied access to the tools and information that prevent unintended pregnancy and HIV infection, or re-infection for women living with HIV.

**Point 2: There is nothing within US law that prohibits integration of RH-HIV**

While the program I visited in Botswana was a so-called PEPFAR program, there is nothing within U.S. law that would have prohibited that program from offering voluntary family planning services and information to the women they served. The United States Leadership against HIV/AIDS, Tuberculosis, and Malaria Act (Global AIDS Act) – the law that authorized and launched PEPFAR (the President’s Emergency Plan for AIDS Release), is silent on the matter of family planning and reproductive health and rights.

In addition to a law that is silent on the matter of family planning, U.S. policies developed and adopted under the current administration support integration:

- PEPFAR’s five-year strategy supports integrating family planning with HIV programs
- The Global Health Initiative (GHI) supplemental guidance on women and gender equality promotes linked and integrated health services
- USAID’s Global Health Strategic Framework incorporates principles of the GHI, including a focus on women and girls and gender equality and integration of services.

Currently, in many U.S.-funded reproductive health programs, you will find HIV prevention services. Yet in a U.S.-funded HIV service, it is rare to find family planning incorporated into that program. So why is this and why is there not more action on the part of PEPFAR to ensure that women, men and youth accessing PEPFAR-funded prevention and treatment funds also address their related reproductive health needs?

**Point 3: the U.S. political climate and fear of cuts to HIV funding are barriers to linking HIV and RH programs and must be overcome**
The only reason that I can find for PEPFAR not explicitly supporting the integration of family planning with HIV programs is the lack of political will and fear of Congressional action to cut PEPFAR funds if they were to pay for family planning.

The current political environment is challenging. There is a war on contraception. And foreign assistance is at risk of cuts. One of Congress’ fiercest opponents of family planning, but a supporter of global health funding, Representative Chris Smith, would likely take action to cut PEPFAR funding if he learned PEPFAR was supporting contraceptive supplies for HIV programs. In 2008, during PEPFAR reauthorization, family planning was included in an early draft version of the bill. It was Chris Smith who held a press conference stating that the PEPFAR bill was now the abortion bill because it included family planning. The fear of Congressional backlash is real.

Yet, it is important to note that integration of RH and HIV is not just about getting PEPFAR funds to pay for family planning. There is a broader and deeper systemic issue that prevents integration from happening — a lack of coordination and leadership among agencies to promote integration. Siloed funding for family planning, HIV/AIDS and maternal health remains a barrier, yet with leadership and will, the siloed funding can and should be funneled into integrated programs [http://www.genderhealth.org/the_issues/women_girls_and_hiv/integration_women_and_HIV/].

Closing point
To advance the integration of RH in HIV programs, we need courageous leadership from the government in- and outside Congress, policy-makers and advocates. Congresswoman Barbara Lee introduced legislation last week – “The Ending HIV/AIDS Epidemic Act” – that includes provisions that would help spur PEPFAR toward more integration of reproductive health services with HIV programs.

With PEPFAR reauthorization around the corner, advocates such as CHANGE, Ipas and others will be able to use the bill as a tool to educate members of Congress about the need for integrated programs under PEPFAR. And we will continue to meet with administration officials to make the case for PEPFAR programs to integrate reproductive health services for women.

There has been a lot of talk at this conference about creating an AIDS-free Generation. If I can leave you with one thing today, it is “not without women, not without reproductive health and rights.”
Advocacy among women affected by and living with HIV in the United States: strategies to ensure our reproductive rights through non-judgmental, compassionate care – Toni Holness on behalf of Tinselyn Simms-Hall, The Women’s Collective, USA

The Women’s Collective, which is active in Washington DC, was not confident that current U.S. policy reflects the real needs that women are living with on the ground. Therefore, in the last quarter of 2011, The Women’s Collective conducted focus-group dialogues with HIV-positive women on the challenges they face when accessing sexual and reproductive health services in the Washington DC area. The goal was to refresh the existing public policy dialogue with the actual and current concerns of real women. The results of these efforts were compiled and compared with similar challenges noted by organizations across the nation. This is a brief summary of the challenges noted [http://www.centerwomenpolicy.org/news/newsletter/documents/REPRO_WomensCollective.pdf].

Health-care provider/pharmacist challenges:
- moral judgment and stigmatization
- lack of coordination between infectious disease providers and obstetricians/gynecologists
- discouraging sexuality, encouraging shame

Policy-maker challenges
- politicization of the sexual and reproductive health and rights of women and using those issues as pawns to advance an alternate political agenda
- absence of women living with and affected by HIV at policy tables
- lack of commitment to sexual and reproductive rights as human rights.

Funder challenges
- influenced by changing political agendas and pressures
- Influenced by taboo surrounding sexual and reproductive services and HIV

Looked at in another way, we found the challenges were related to:
- COMPASSION: moral judgment, an emphasis on the unborn child, discouraging sexuality & pregnancy
- COORDINATION: creates difficulty in understanding the connection between HIV and SRH issues
- STIGMA: complicates women's decisions to disclose their status and obtain SRH services and affects their ability to talk to partners and negotiate with partners
- SOCIOECONOMIC, SOCIAL and DEPENDANCY ISSUES: housing, economic dependency, addiction, and lack of social support make it difficult to deal with SRH issues.
To speak to the diversity of local and national leadership, we recognized that women living with HIV must be included in decision-making bodies in meaningful ways to ensure that their sexual and reproductive health issues are adequately addressed.

To meet this need, we started PLUS, which:
- brings the voices of women living with HIV/AIDS to decision-making tables and broader communities
- works to reduce the role of all forms of violence against women in the spread of HIV/AIDS
- works in collaboration with advocates and organizations to ensure the protection of HIV-positive women’s human rights
- educates communities about housing, jobs, health, education and safety as tools for prevention and support
- continuously improves their advocacy skills through training, volunteering and networking.

PLUS is intricately involved in our sexual and reproductive health justice advocacy. We believe in keeping the voices of positive women alive in the advisory and decision-making process. PLUS advocates have:
- created and led local SRH awareness campaigns
- presented at local and national conferences
- met with the head of the Office of National AIDS Policy
- testified before the President’s Advisory Committee on HIV/AIDS.

The Women’s Collective’s sexual and reproductive rights work has included the following:
- Development of a sexual and reproductive health and justice toolkit for providers, women and policy-makers. The toolkit is informed by the actual experiences of HIV-positive women. By channeling the voices of HIV-positive women, the toolkit hopes to inform the current policy dialogue with the current and actual sexual and reproductive health and justice experiences of HIV-positive women.
- Presentations for local and national providers, advocates and stakeholders.
Advocacy on funding restrictions for SRH services, policy efforts to restrict women’s reproductive rights, and the need to increase positive women’s voice and presence in national policy conversations. Two examples:
- We warned about the danger of Arizona House Bill 2625, which compromises the sexual and reproductive health rights of women living with HIV. It permits employers to demand a medical explanation for a women’s contraception use and sanctions employers to terminate women who use birth control for “non-medical” purposes.
- We sent a statement criticizing an attempt to defund Planned Parenthood educating providers.

Activities in informing key national efforts: NHAS, PACHA work, DV-HIV integration, for example, we pushed PACHA to convene a special meeting on the needs of women.

Connecting with local and national advocates to increase women’s voice:
- coordinating local and national marches: WE CAN END AIDS, Save Our Safety Net
- founding member of the 30 for 30 campaign, which is dedicated to ensuring that the unique needs of women living with and affected by HIV, including transgender women, are addressed in the national HIV response.

The Women’s Collective would like to make the following recommendations:
- Policy-makers: ensure meaningful participation of women living with HIV in the policy dialogue.
- Providers: offer gender-focused and culturally competent services that are supported by sustainable and sufficient resources and integrate SRH, gender-based violence, and HIV services.
- Researchers: take a more gender-focused approach that addresses the social and structural vulnerabilities that are unique to women; develop women-controlled prevention tools.

DISCUSSION

The discussion centered on questions posed by delegates and the chair.

As far as women living with HIV and their access to reproductive care is concerned, how is violence a barrier to access?
- Marie: violence among women living with HIV/AIDS is very high. When a woman finds out that she is HIV-positive, the whole community knows, and access to information and health-care services gets more difficult. If that woman is married, the man feels free to go out and look for other women and she cannot do anything about it.
- Jennifer: from the Namibian context, gender-based and domestic violence rates are very high, not only for women living with HIV. We have harmful cultural practices that affect all women and high rates of incest. Many women are left without any information or choices.
Serra: from the policy perspective, PEPFAR is putting a lot of money into gender-based violence but without the link to RH health care, it’s frustrating. This needs to be added to the advocacy agenda.

In terms of advocacy happening here in Washington DC around the PEPFAR reauthorization, where can contributions be made?

- Serra: advocates have started to informally meet and discuss what we would want in the reauthorization (the Lee bill). It’s difficult to know if we should just ask for a continuation of the program as it stands, or if we should open it up for revision and let different stakeholders add their voices in a tough political context.
- Jamila: in terms of advocating in Washington DC, discussions around the reauthorization need to be strategic and calculated to make sure that we have the best bill possible and to make sure that women and men living with HIV are not undercut by politics.

What do your organizations do to involve men in intimate partner violence discussions?

- Jennifer: in Namibia, we have very good policies around gender-based violence but implementation is poor; we need to see political will taking its course. We did start youth outreach programs to involve young men because they are more open to recognizing gender-based violence. These young men then influence some of the older men and we’ve had incidents where young men have stood up against gender-based violence.
- Toni: at The Women’s Collective, our work for families includes men and we encourage them to take part in prevention. We give negotiating tools to women to get men on board with women-centered approaches.
- Marie: It’s not easy for men to come and talk with women about violence, but we are trying to engage them in our activities. For example, in Mzuzu, we have men participating in ICW activities.

We often hear that we need to have women at the table, but at the same time we know that women have very busy lives. What strategies do you use to encourage women to take on an advocacy role?

- Jennifer: it is helpful to have a structure in place. Women themselves have formed groups that allow us to come in and educate women about Namibian laws and policies so that they can advocate for themselves. We have held 2-day community dialogues where we work first with women and men separately, then with community leaders, and then we bring all of the groups together. Through this process, we have seen great results and responses from men.
- Toni: peer support is a huge factor. If one woman is very comfortable speaking in public forums, she can reach out to another woman. We don’t ask women to speak out but support them in undertaking advocacy at their own pace and create opportunities whereby women can step up when they are ready.
- Serra: at the country level, we’ve conducted advocacy trainings with women living with HIV and support them go to meetings with the U.S. missions to share their stories and influence decisions at the mission level. Here in the U.S., we have brought domestic and foreign women living with HIV to Washington DC to meet with Congressmen and
women; we brought some of the same women back this year to a communications training.

- Jamila: Ipas is also working with health-care providers who have taken on the role of advocates for the women that they serve. Mostly these are nurse-midwives who advocate among providers, but they also include obstetricians-gynecologists. We work in the community with women and provider advocates to make sure that women get family planning services after they have received care for their unsafe abortions. The providers learn through their patients and become strong advocates on many levels.
- Marie: Normally to involve women, we work through structures that they have created and we give them the chance to speak about their experiences. These women feel strongly that they need access to family planning.

Are any of you addressing abstinence-only programs in PEPFAR reauthorization?

- Serra: Barbara Lee's bill does address this in order to ensure that money does not go to abstinence-only education. Addressing this issue depends on the bill being discussed as well as the administration in terms of pushing for comprehensive sexuality education.
- Jamila: there are steps that the administration can take that do not need a legislative change or an act of Congress. There are ways to make sure that we are providing the most comprehensive programs possible within the confines of our current legislative climate.

Websites of the participating organizations (ICW Malawi does not have one):

CHANGE  
http://www.genderhealth.org/

Ipas  
http://www.ipas.org/

Namibian Women's Health Network  
http://www.namwhn.org/

The Women's Collective  
http://www.womenscollective.org/