

ATHENA NETWORK AND THE GLOBAL COALITION ON WOMEN AND AIDS

UNGASS High Level Meeting on AIDS:

Virtual Consultation March 2011



With the UK collaboration of:

Making a difference in HIV
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Sophia 



Key issues and findings from the UK

April 2011

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GIPA – Greater Involvement of People living with HIV

There is a strong need for sustained funding and support to HIV-positive women's organizations and networks which provide vital information, support, services and advocacy.

Opportunities for participation in decision-making for the majority of women living with HIV, and particularly outside of London, are extremely limited. Stigma and discrimination are factors inhibiting greater participation, but also lack of consultative mechanisms, and lack of funding to support networks of women living with HIV, and key affected or marginalized populations of women who may face multiple burdens of stigma and discrimination

'The sad fact is that while there are a very few very vocal women activists living with HIV who are mostly employed (waged) in cities by HIV activist and support organisations such as Positively UK, Pozfem UK, ICW etc The rest of us, especially in rural areas have no voice at all.'

'Communities of people who use drugs although disproportionately affected by HIV, remain very rarely engaged in decision-making processes, particularly at the national level.'

SOLIDARITY

There is an urgent need to address HIV-related stigma and discrimination in the UK, through better public awareness around HIV, less of a focus on 'high risk groups' and activities, and through decriminalization of HIV transmission and drug use. Better public health education should be implemented including in schools and workplaces.

'We had a woman with HIV talk to our class when I was a school. She came in to talk for an hour, but made such an impact on us all that her message to us was life-changing.'

While bio-medical services for women living with HIV – including support with pregnancy and vertical transmission services – are of a high standard, there can be a lack of knowledge about these services, and a lack of psycho-social support around them.

Stigma and discrimination within health services must be eliminated, and efforts to ensure that HIV-positive women seeking immigration or asylum, or those in prison, have better access to sexual and reproductive health services

SAFETY AND SECURITY FOR WOMEN AND GIRLS

There is an urgent need to better understand the intersections between violence against women and HIV and to address these through scaled up efforts to address all forms of intimate partner and gender based violence against women and girls, including sexual violence and rape. There needs to be better linkages between HIV services and services addressing violence against women, including rape.

There are still cultural and social barriers to women and girls buying (male) condoms and negotiating condom use. These need to be addressed. Further, women who seek contraceptive advice from their GP are not always warned about risks of HIV and STI transmission, or advised to use dual protection.

'condom access is good but ability to negotiate is poor. Among sex workers I believe it may be better, but with regular partners, maybe not.'

'There is a huge social barrier for women in the UK to take control and insist on condoms.'

GENDER EQUALITY

Gender needs to be addressed in the HIV and Sexual Health Strategy, and there needs to be full realization and enforcement of existing human rights legislation so that no woman is denied access to health care or placed at increased risk of exposure to HIV on the basis of her gender. There is need for a better understanding of gender issues in relation to HIV and in general, and there needs to be more support for women's groups including HIV positive women's networks and support groups.

'Even though this is the UK, there is little awareness of gender equality and little connection between general women's groups and HIV-positive women's groups'

INTEGRATED SERVICES

Health policy and services seem to focus on prevention of unwanted pregnancy, and this leads to neglect of prevention against HIV and other sexually transmitted infections.

'Testing is almost always only available for women through Ante-Natal Centres.'

There is an urgent need to ensure that marginalized women, especially women in prisons, asylum seekers, women who use drugs and women in sex work have access to comprehensive integrated HIV and SRH services, including gender-sensitive harm reduction services.

Fear of disclosure, stigma or discrimination still acts as a powerful barrier preventing women, especially young and marginalized women, living with HIV from accessing comprehensive services. This is exacerbated by fears around criminalization of HIV transmission.

Women need to be more aware of what services are available to them,

'i'm afraid i am in the dark on most matters relation 2 the above. asian women in this country will not be aware of what services are available 2 them.'

ANTE-NATAL CARE

Opt-out testing is available to all pregnant women who come in for ante-natal care. Any woman testing positive in ANC will be offered prevention of vertical transmission services, though the quality of the services may vary according to location, and there needs to be concerted efforts to ensure that quality vertical transmission services are available to marginalised women.

'Again, care in the UK is very patchy. Some good centres but very rare and only in a few major cities.'

Women living with HIV in some areas are well supported to pursue and achieve their fertility desires, but this is a long way from being universal.

WOMEN-CENTRED TECHNOLOGIES

There is a need for greater accessibility to women-centred prevention technologies. Female condoms are more expensive and less generally available than male condoms, and women need better negotiation skills to be able to effectively use either.

'prevention technologies are useless if women do not have the confidence and skills to negotiate them with their partners.'

Knowledge about the availability of Post Exposure Prophylaxis (PEP) is patchy; it is issued to health workers exposed to HIV, but non consistently to rape survivors.

'PEP is hardly available.'

'All women raped are offered an HIV test and prophylaxis treatment'

'No idea of most of this - which is saying something in itself as if I have not heard of this happening as an out women living with HIV, then it probably is not happening in my rural area'

Positive women's networks need support to be able to disseminate information about important technologies to women living with HIV, and also to work with hospital and clinic staff, but funding for networks is scarce.

EDUCATION: SEXUALITY EDUCATION

There is a strong need for comprehensive sexuality education, which includes all aspects of sexual health including HIV awareness and prevention, delivered in a non-threatening and non-stigmatising way, and equally accessible to young women and young men, from a young age. HIV awareness and prevention packages that target young women in particular should be developed. Comprehensive Sexuality Education (CSE) should also include different identity needs for lesbian, gay and bisexual young people.

Outside of formal education settings there is a need for public health education and awareness around HIV and safer sex

Youth-friendly services are patchy, and there are very few services targeting young people living with HIV. Young women – including young women living with HIV need more support around their sexual health and fertility, including through increased self esteem and empowerment.

'Young positive women do not have enough support around sexual health and many have unintended pregnancies.'

CARE

Support for people living with HIV needs significant strengthening, in particular in rural areas, including emotional and psycho-social support. For example, more funding is needed for voluntary support groups. Care work in the home or community in general needs to be recognized.

'I get absolutely no emotional and personal support in my rural area.'

'If I try to get support even from the clinic that gives me medication I am treated like I have no reason to ask for it'

There is on-going stigma within health services; GPs in particular need better training and awareness about HIV; people living with HIV working in health services are extremely stigmatized.

'I was refused a job as a medical secretary after disclosing my status.'

APPROACHES TO ALL WOMEN AND GIRLS

There needs to be more research into how HIV affects women; this needs to go beyond the interactions of HIV and pregnancy. Women should be included in clinical trials

Universal access to prevention, care, treatment and support is still not being achieved in the UK. Efforts to ensure that men, women and children seeking asylum or within unsettled immigration status have access to ARV are particularly pressing.

NOTES

These survey results were gathered as a part of a global virtual consultation of women in relation to HIV as a part of preparations for the UNGASS High Level Meeting in June in 2011. The information here provides preliminary analysis of responses from women in the UK.

Women living with HIV now account for 39% of all people with HIV in the UK

Overall, the virtual consultation has received responses from over 700 women in over 95 countries from all 8 regions of the world, as defined by UNAIDS. The Survey for consultation was translated into 9 different languages.

Active involvement of focal points and technical experts from these 8 regions (15 of whom have been brought into the process as paid consultants, underscoring and validating the principle of investing in women).

Wide consultation and validation of the survey tool was undertaken at the 2011 Commission on the Status of Women in New York in February 2011.

Preliminary regional findings fed into the Latin America, East and Southern Africa, West and Central Africa, Eastern Europe and Central Asia, Caribbean, and Asia and Pacific regional civil society meetings in the run-up to the Civil Society Hearings held in New York on 8 April 2011.

Involvement of positive women/positive women's networks both as organizers/consultants/facilitators/translators and also as respondents (over half of our team is comprised of women living with HIV1 and among respondents, an average of 40% are women living with HIV).

Involvement of other key affected women as consultants/facilitators/translators and also as respondents (recognizing that many women carry multiple identities:

- women living with HIV 40%;
- young women approximately 30%;
- lesbians approximately 10%;
- women engaged in sex work approximately 10%;
- women who use drugs approximately 20%;
- women living with disabilities approximately 10%;
- caregivers approximately 20%;

as well as participation by women who have been in prison or detention centres, homeless women, and transgenderwomen)

In the UK, this survey was actively supported by the following organizations and networks, in alphabetical order:

Positively UK: www.positivelyuk.org

PozfemUK: www.poz-fem-uk.org

Salamander Trust: www.salamandertrust.net

Sophia Forum: www.sophiaforum.net

All the regional survey summaries can be found at http://www.womeneurope.net/index.php/page/SURVEY_on_HLM_/en

In the UK, there are three key organisations and programmes that actively promote and support the issues highlighted by women from the UK in this survey.

These are PositivelyUK, including the ground-breaking peer-led motherhood mentoring project, entitled "[From Pregnancy to Baby and Beyond](#)"; [Pozfem-UK](#), a network of HIV positive voluntary women advocates; and the [Sophia Forum](#), the UK Chapter of the UNAIDS Global Coalition on Women and AIDS.

To read and hear more about all these organisations/networks and our work, please follow the hyperlinks above.

Investment in networks of women living with HIV and the organisations that support us is a hugely critical issue around the world, no less in the UK. The most recent edition of PositivelyWomen magazine ([spring 2011](#)) focuses on this issue.

POLICY BRIEF

Last but not least, over 60 networks of women living with HIV from around the world have just launched a Policy Brief, calling on donors and policy makers to invest in our networks. This Policy Brief can be viewed at http://www.womeneurope.net/index.php/page/Policy_Brief_2011/en