

WECARE+...

Moving forward the Positive Women's Agenda, linking across Europe and Central Asia

Alice Welbourn introduces WECARE+ and the thinking behind it

It may seem strange to hear, but there has never been a formerly registered network of positive women reaching across this Northern continent, which is to be home to the next International AIDS Conference³. There was pioneering and courageous activism of some key European women living with HIV in the early days of HIV, through starting Positively Women in the UK and, after that, the International Community of Women living with HIV and AIDS⁴. Since then, however, there has been relatively little development of regional HIV activism, especially by and for positive women in Western Europe, compared with that of other corners of the world. In Eastern Europe and Central Asia there is ECUO – the East Europe and Central Asia Union of People living with HIV and AIDS⁵. And there is the Global Network of People living with HIV and AIDS Europe Region⁶. But neither of these groups to date has a specific European sub-grouping for women with HIV.

In 2005, Marijo Vazquez of Creación Positiva⁷ in Spain and ICW, I and other colleagues in Europe, discussed the idea of setting up a network of positive women across Europe, to complement the great work of other regional positive women's networks. No doubt, others had had this idea before us. Until now, however, other priorities have always seemed more pressing. Finally though, with the pressing advent of the

Vienna Conference, we have decided that it is time to seize the opportunity and act now to rectify this.

What reasons are there for a lack of a European structure? We think there are multiple reasons. Language is one – there are so many different languages in Europe. Another is that relatively, women in Western Europe at least are, of course, much wealthier than on other continents. Thus, it is assumed that women face greater challenges elsewhere than in Europe. This is true to some degree. However, many studies have shown that quality of life is most affected not by absolute poverty but by *relative*

poverty⁸, in relation to others around you.

This means that many women, especially women who are single mothers, for instance, can feel socially excluded, because they are not able to take part in the kinds of normal social activities that others around them with children are able to afford. So by this scale, many women living with HIV are still very poor and disadvantaged, even in Western Europe. But because Europe is seen as a rich

continent, there is extremely little funding available to support positive women in Europe and most of our work has to be done on a voluntary basis – just as elsewhere.

A third reason is that treatment availability has, ironically, pushed HIV underground. People have assumed that because treatment is available, HIV is sorted out and that stigma would become history. Of course we all know that this is not the case, but it is hard to explain to others.

HIV in Europe is also a challenge, because the overall

**...we trust that we can
redefine, recreate and
sustain a more humane
response to HIV...**

numbers of women with HIV are still low compared with elsewhere – so HIV is seen as a minor problem, not relevant to most people. Moreover, the majority of people with HIV in Europe are still gay men, and people are often amazed to hear how many women have the virus. Women with HIV in the region also come from many diverse backgrounds. There are probably women with HIV in Europe from all corners of the world. Furthermore, the increasing challenges of HIV transmitted through injecting drug use are particularly large in Eastern Europe, where there is still little scientific and human rights-based harm reduction provision. As a result, HIV understanding in Europe is limited, as it is seen as a ‘foreigner’ or a ‘gay’ or a ‘junkie’ disease, associated with high levels of stigma to do with race, homophobia and other misunderstood health issues.

There are also increasing numbers of older women who acquire HIV from their long-term partners or, if divorced perhaps, after a holiday romance, discover that they are HIV

...the ‘double whammy’ of being an African woman living with HIV...

positive. They dare not speak out about their HIV status for fear of shame or ridicule, and also for fear that their children may no longer allow them to cuddle their grandchildren.

Some positive women who have been powerful activists in the past, have decided to move back into private life, in order to raise a family or start a new

...the enormity of the challenges, which even the ‘developed’ world still needs to address...

relationship, without being in the public eye. Given the stigma in Europe, this is entirely understandable and their rights to do this need to be respected. At the other end of the scale, younger positive women who are just starting their adult lives are fearful of being open about their status, because of the effect it might have on their ability to form relationships, have children or develop their careers.

For all these reasons, many women with HIV just want to get on with their lives, protect their children, keep their jobs and not speak out about their HIV status, because the risks of their disclosure are so huge. So ironically in many ways, HIV for women of all ages is still very hidden – and is also a huge problem for us in Europe, despite Europe calling itself the ‘developed’ world.

The Vienna Conference offers us therefore a rare opportunity to turn the spotlight of the world on what is happening in Europe, to raise awareness of European governments, professionals, the media and society to what is happening in their own region, to change attitudes, policies and practices towards women with HIV in Europe and Central Asia – and globally – and to reduce women’s and girls’ vulnerability to HIV in Europe.

In preparation for Vienna, a number of positive women activists from across Europe have decided to form ‘Women in Europe and Central Asia Region Plus’ – ‘WECARE+’ for short. This decision emerged from a side-meeting for positive women only, held during a larger landmark meeting of European agencies working on women and HIV, in Vienna, in October 2009.⁹ We also resolved to seek funds to appoint a European Regional Coordinator, who would be an openly positive women, based somewhere within the region, most likely in the country of her origin, to work on advocacy issues across the region.

Of course in Europe and Central Asia, as elsewhere, positive women have been doing amazing things with virtually no resources.

As Sophie Dilmitis of World YWCA¹⁰ reports:

This meeting was an incredible experience to hear first hand what women are going through in Europe.... People from Austria set the scene in saying that there are around twelve to fifteen thousand people living with HIV in Austria and half of these live in Vienna – but there are no figures on women living with HIV in Vienna. The person who delivered the presentation has been living with HIV for 14 years and is the only positive woman who is open about her status in Vienna. People experience stigma and discrimination especially in the medical services. There are also not enough doctors to support all the positive people in Austria and they need more active people to fight for rights and address stigma and discrimination.

Women will come to a support group but will not disclose their HIV status. Women are mainly infected by heterosexual contact and through drug use. There are also issues in prisons and there is Hepatitis C and B co-infection. Another issue is that sex workers have to register to do this work and they then have to have a weekly check up. If they are diagnosed HIV positive they lose their licence to work and then they are not protected at all by laws that protect sex workers and they still continue to engage in sex work. Also as women with HIV are aging, the health system is not geared to deal with this in Austria. An organization was founded last year for women and HIV in Austria and unites all the experience of women living with HIV and people from the pharmaceutical

industry and concerned people who want to get involved. They have already had a national meeting of women to understand the situation of women as people seem to be working in silos and are not sharing information. This group supports women irrespective of their HIV status.

Vienna is one of the world's most rich and cultured cities. It was also host to the UN World Conference on Human Rights in 1993. As Charlotte Bunch¹¹, Founding Director and

Senior Scholar at the Center for Women's Global Leadership, explains:

...they dare not speak out about their HIV status for fear of shame or ridicule...

Human Rights – *Women were primarily seen as part of the social and economic work of the*

UN, and women's rights were only rarely addressed in the human rights arena before the 1990s. The change in this perception came most forcefully at the UN World Conference on Human Rights in Vienna in 1993. With the cold war over and the issue of rape in war gaining media coverage in Bosnia, women seized the opportunity to demand attention to women's rights as human rights. They organized across the North-South divide and in all the regional preparatory processes to ensure that the Vienna Declaration and Programme of Action included a strong affirmation of the rights of women as universal human rights, and in particular for the recognition that all forms of violence against women are a violation of human rights.

One of the specific demands in Vienna was for a Special Rapporteur on Violence Against Women, its Causes and Consequences to report to the Commission on Human Rights (CHR) in Geneva. This Rapporteur was appointed in 1994, and her annual reports have elaborated human rights standards on VAW and outlined government's responsibilities to abide by those standards in concrete policy terms, following the parameters outlined in the UN Declaration on VAW. Another call from Vienna was for gender integration into all the work of the human rights machinery – the subject of annual resolutions at the CHR since 1994 and now at the Human Rights Council. The Office of the UN High Commissioner for Human Rights (OHCHR) has included a mandate for gender integration from its inception, and a growing number of human rights treaty bodies and special procedures have given attention to the gendered aspects of their mandates, including the Committee on Torture and on Racial Discrimination.

A number of gender related human rights issues have raised important but difficult debates and controversies. The discussion of sexual rights is implicit in the Vienna, Cairo, and Beijing World Conference documents, where reference is made to the right to control over one's sexuality...

So it is hard to hear about the situation

...people are often amazed to hear how many women have the virus...

...HIV is seen as a minor problem, not relevant to most people...

facing women with HIV in Austria now, 17 years on from this World Conference, especially as it prepares to host the next International AIDS Conference.

By contrast, the former Soviet block countries experience immense poverty. As Silvia Petretti¹² reported:

...the reports from Eastern Europe were quite chilling. The women from Russia were among the youngest in our group, mainly in their early twenties, but nevertheless, you could see really motivated activists. Russia has one of the fastest growing and largest HIV epidemics in Europe. The official numbers from the government are low, a few hundred thousands, however WHO estimates there are over 1,000,000 people living with HIV and 38% of those are women. The women at our meeting highlighted that even if heterosexual transmission and intravenous drug use are the main routes of transmission, shockingly, some women also [acquire HIV] in hospitals, because of lack of universal precautions. They also talked about the immense lack of resources, especially for women in prison, who don't have absolutely any access either to prevention or treatment.

Stigma and discrimination are rampant in Russia, and among the general population there is still the false perception that HIV only affects drug users and 'prostitutes'. If the women are drug users and want to access HIV treatment they need to register as drug users and this puts them at risk to lose custody of their children. Therefore women often get

really sick and die, because trying to access medication could lead to being separated from their children.

Wezi Thamm from the UK spoke of the 'double whammy' of being an African woman living with HIV. There are huge

...it is hard to explain to others...

trust and confidentiality fears for African women who are also dealing with being far from home, often having lost family members through conflict or AIDS, facing racism and many other related issues. It often seems

hard to get anyone to take these stresses seriously. In the UK, 78% of women living with HIV are from high prevalence countries. Moreover in the UK, there are women with HIV and their children held in asylum centres without access to ARVs.

In the middle of Europe, as described by Silvia Petretti:

Something that was really shocking for me is what has been happening in Albania. I know that it is one of the poorest countries in the EU, but it is also really close to Italy, just a few miles across the water. I couldn't believe the story one woman [Olimbi¹³] told. A mother of 4 children, 3 of them HIV+. They all got diagnosed after her husband (who had never disclosed to her) died of AIDS in 2004. Two of the children were also really sick, and nearly died because they couldn't get treatment. I just cannot believe that this was happening a few miles from Italy

in 2004. This woman fought like a lioness for her and her children's rights to treatment, and for once this story has a happy ending and they got their meds in the end and survived. She is now one of the heads of the movement for the rights of PLHIV in Albania.

Other issues faced by positive women in Europe and Central Asia echo those in many other parts of the world. These include sexual and reproductive rights issues; feared and real physical, sexual and psychological violence from partners, especially on disclosure; threats of criminalisation; fear around disclosing to new partners and of starting new relationships; young positive women's issues (about which there is barely any information); issues facing women in prison; LGBT issues; and chronic depression.

Many more stories were told – too many to include here, but we hope that this short article has given a flavour of the enormity of the challenges, which even the 'developed' world still needs to address in its attitudes and practices towards women with HIV. This is why WECARE+ has been set up.

Finally, our initiative in Europe and Central Asia is designed, we hope, not only to benefit all women and girls

...there has been relatively little development of regional HIV activism, especially by and for positive women in Western Europe...

within our region, but also to benefit other women and girls around the world – and ultimately all with whom they relate. Since the European Union is the single largest donor to world aid after the US Government, there is much that we seek to do to hold all the Western and Eastern European states and the European Union to account for both their domestic track records and their international donor commitments to the rights of women worldwide. Although there is much to admire and appreciate

about Western governments' practices, there is also much room for improvement.

The strapline for the Vienna International AIDS Conference is '*Rights Here, Right Now*'. We hope and trust that the Vienna AIDS Conference will offer us all the opportunity to reassert the human rights of women as a core part of universal human rights, as declared in Vienna back in 1993. We hope and trust that this International AIDS Conference will enable a diverse range of civil society across our region to engage with donors and policy makers alike. Together we trust that we can redefine, recreate and *sustain* a more humane response to HIV, for the benefit of us all.

FOOTNOTES:

1. With thanks to Sophie Dilmitis, Silvia Petretti and Wezi Thamm for their contributions to this article.
2. Alice Welbourn is supporting women across Europe and Central Asia to launch WECARE+.
3. [www.aids2010.org/]
4. [www.icw.org/about-ICW]
5. [www.ecuo.org]
6. The GNP Europe region is yet to have its own website. [www.gnpplus.net/content/view/1550/125/]
7. [<http://creacionpositiva.net/>]
8. See, for instance, further discussion and explanation of these terms at [www.poverty.org.uk/summary/social%20exclusion.shtml] and at [http://news.bbc.co.uk/2/hi/uk_news/6361349.stm]
9. At this side meeting, we decided to register WECARE+ centrally in the region – in Germany. We also decided to form an interim initial voluntary board of trustees for this group from right across the region, of whom a minimum of 80% would be openly HIV positive. (This initial interim board will be replaced by a fully elected board after an initial year.)
10. [www.worldywca.org/]
11. Bunch, C. 2009: 'Women's Rights and Gender at the United Nations: The Case for a New Gender Equality Architecture'. (to be published in Vereinte Nationen: German Review on the United Nations, 2009)
12. [<http://hivpolicyspeakup.wordpress.com/2009/11/13/women-in-europe-vienna-2010-and-beyond/>]
13. To read more about Olimbi and her work, see www.sophiaforum.net/index.php/News/House_of_Commons.

Alice Welbourn is a UK-based activist, writer, networker and trainer, who was diagnosed with HIV in 1992. She currently serves as the Chair of the Sophia Forum – the UK Chapter of the Global Coalition on Women and AIDS and is Founder and Director of the Salamander Trust. For more information and/or comments, please contact her at alice@salamandertrust.net.

Women in Europe and Central Asia Region Plus – WECARE+

We welcome all of you living with HIV in Europe and Central Asia to join us.

We have started a closed listserv for HIV positive women who live in Europe and Central Asia only. If you fit these criteria and would like to join this listserv, you are most welcome.

Please contact wecareplus@yahoo.com.

We also have an open, multi-language website for anyone to visit and share information at www.womeneurope.net

PS: WECARE+ is urgently in need of funding to develop our activities across Europe.

If you are able to support us, we would be delighted to hear from you.