

PozFem UK: Women, HIV and Sexual Health in the UK



PozFem UK: the National Voice of Women Living with HIV

PozFem UK is the only national network of women living with HIV. It was established during *Changing Tomorrow*, the UK conference of people living with HIV, held in Leicester in September 2004. PozFem UK works through 20 HIV positive regional coordinators who are linked to regional groups around England, Northern Ireland, Scotland and Wales. The International Community of Women living with HIV/AIDS (ICW) and Positively Women provide technical support to PozFem UK. PozFem UK is an initiative that is funded by the Big Lottery Fund.

PozFem UK

- provides a support network particularly to women who are geographically isolated or in prison;
- keeps women informed of HIV, health and psycho-social issues;
- sensitises policy makers and service providers to the issues faced by women living with HIV;
- creates a link between experiences and challenges of women living with HIV, at local, national and global levels.

Background to this paper: the 2008 review of the UK's National Strategy for Sexual Health and HIV

Better prevention, better services, better sexual health – The national strategy for sexual health and HIV was published by the UK Government in 2001¹. An implementation action plan was developed in 2002, and in March 2003, the UK Public Health Minister announced the establishment of an Independent Advisory Group on Sexual Health and HIV (SHIAG), charged with monitoring and advising the Government on the implementation of the National Strategy.

In its annual report for 2006/7, *Why sexual health is a cross governmental issue*², SHIAG recommended a review of the National Strategy because of rapid changes within the National Health Service, and their impact on sexual health services. MedFASH (the Medical

Foundation for Aids and Sexual Health) was charged with coordinating the Strategy Review.

Who is this Vision Paper for?

This Vision Paper came about as a result of PozFem UK's involvement in the Strategy Review, and accompanies our formal input to that process. However, it has far wider relevance. It documents concerns and recommendations raised by members of PozFem UK on the basis of our personal experiences and illustrates these with quotes from PozFem UK meetings, as well as ICW and Positively Women's publications. We hope it will serve as a useful advocacy tool for HIV positive women around the UK.

We believe it is crucial to ensure that our experiences as HIV positive women inform policy, and we feel strongly that the issues we raise here are important

and relevant for a range of policy-makers, service providers, voluntary organisations and activists involved in gender equality, sexual health and HIV.

PozFem UK and the Strategy Review

Following the suggestion of SHIAC member and Executive Director of Positively Women, MedFASH agreed to involve HIV positive service users in the Strategy Review, and a consultation meeting with PozFem UK was organised.

The meeting was set up at relatively short notice. Fourteen women attended the consultation meeting in London in January 2008. UK regions represented were: Northwest England (3), Yorkshire (1), London (3), Southeast England (1), Southwest England (2), the Midlands (4). Nine participants were black, and five white, and all were HIV positive women.

Participants were sent relevant documents before the consultation, and given guidance on preparing for the meeting. A PozFem UK pre-meeting enabled participants to discuss together and build our collective ability to engage with the consultation process and raise issues of most concern as HIV positive women. Our input to the Strategy Review is available from PozFem (www.poz-fem-uk.org), ICW (www.icw.org) and Positively Women (www.positivelywomen.org.uk).

PozFem UK's alarm bells for policy-makers

Worldwide, HIV increasingly affects women. In Africa, latest UN figures show that over 60% of HIV infections are among women, with young women up to six times more likely to be infected than young men³.

In the UK, the number of women diagnosed each year with HIV is rising. In 2006, 73,000 people are estimated to



Members of PozFem UK

be HIV positive, of which 35% are women. In 2006, 40% of new diagnoses were in women (2,834/7,093), up from 25% of new diagnoses in 1997 (678/2,764)⁴.

The attention of the British public has been focused for many years on people living with HIV in less economically developed countries, where people living with HIV commonly experience a gross lack of access to care, treatment and support. Whilst this focus is valid and necessary given the magnitude of the impact of HIV in these countries, we are concerned at the lack of understanding of the issues facing women living with HIV in the UK.

As PozFem UK members and women living with HIV in different parts of the country, we feel it is vital to sound a number of **alarm bells** in relation to sexual health and HIV, and the policies and strategies which are guiding the UK's national response.

1. HIV testing

1.1 The trauma of testing positive

Receiving a positive HIV diagnosis is extremely traumatic. For women, disclosure to partners can be particularly difficult and sometimes dangerous (see also section 6).

Ongoing advances in new treatments are prolonging the lives of many people living with HIV in the UK. However, the shock of being diagnosed HIV positive – and the lack of solidarity and understanding which accompany HIV – is an often unacknowledged area of our lives. Medication has transformed many HIV positive women's lives, but it has not converted stigma and discrimination into solidarity and support, or eradicated violence when we disclose to our friends, family and partners.

“For the first and only time in my life I contemplated killing myself “

Alice, Good Housekeeping, March 2008

“The shock was enormous. There were tears. I went terribly quiet and immediately retreated, withdrawing into



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Silvia

a world that took me nearly five years to return from. Sometimes I feel as though I still exist there. A place that is lonely, shameful, and damaged, where my own body is my enemy and the person I blame is myself.”

Esme, Positively Women Magazine, Spring 2008

1.2 Assumptions about who is “at risk”

Medical professionals may have fixed ideas about who will and will not be likely to be HIV positive:

“When I first fell ill I was misdiagnosed time and time again in 2004. My local GP apologised, but even the consultants misdiagnosed me. No one tested me for HIV until my partner was diagnosed. Even though I had tell-tale signs such as aggressive mouth and throat thrush, no appetite etc. Surely GPs and consultants should be better educated and able to ensure people are tested before weeks and weeks of illness.”

PozFem UK member, January 2008

1.3 Routine antenatal testing – the impact on women

Under the UK's policy of routine HIV testing of pregnant women attending antenatal clinics, the Health Protection Agency reported that in 2006, antenatal testing accounted for 15% of all women diagnosed in the UK. PozFem UK members believe that the negative impact on women of an HIV diagnosis in pregnancy may often outweigh the benefits.

“I was diagnosed during pregnancy but I just was too scared to tell my partner. It was too much...I was scared he would leave me and being pregnant I couldn't deal with it. After the baby was born I convinced my partner to go together for testing and I pretended I didn't know. To this date I couldn't tell my partner.”

PozFem UK member, January 2008

"I found out my HIV diagnosis when I was eleven weeks pregnant with my second child in March 2002. I wondered why did I agree to have the test in the first place? I didn't think it could ever happen to me, I hoped it was a complete mix up with someone else's blood. A feeling of fear, shock and devastation came over me, thinking that I may also have passed the HIV on to my five-year-old daughter, and my husband..."

Eileen, Positively Women Magazine, Spring 2007

A woman who was diagnosed during an antenatal check up recounts:

"I decided that I would keep my baby, but when I told my husband about the HIV the first words out was that we should have an abortion – I said no. His blood was taken and the result came a week later. [...] His result came back negative and everything changed. He kept going on about an abortion, life was a living hell, it was an everyday thing. He would not sleep in the same bed with me and when he did he would jump or ask me to move away if I mistakenly touched any part of his body[...]. The doctors were wonderful and my daughter was successfully delivered. Now the physical abuse started in my home. One day he came into the room where I was feeding the baby. When I refused to put her down he held me by the throat and started choking me. Then came the punches, on my head, face, my tummy, it was everywhere. [...] The violence continued, I was taken to A&E for head injuries after he had punched me and I passed out. I could not tell anyone because he kept threatening to tell friends and family about my HIV status so I remained with him and the abuse..."

Patience, Positively Women Magazine, September/October 2002

Given the traumatic nature of receiving an HIV diagnosis, and the increased risk of violence and abuse by partners and others, PozFem UK members feel strongly that the general policy should

be to offer women testing before they conceive, not while they are pregnant. We emphasise the importance of pre-test counselling, and we are concerned by the move towards pre-test "discussion" (or less) to replace pre-test counselling.

1.4 Counselling and support

Any scale up of wider HIV testing must be accompanied by firm measures to improve support and solidarity for HIV positive people, and to reduce associated stigma and discrimination. Specific, gender-sensitive support and counselling must be made available for women testing HIV positive. This should include women who use legal and illegal drugs – injecting or otherwise, and for whom good post-test counselling might help avoid adverse effects such as increased drug/substance use. Voluntary sector organisations providing this kind of support – particularly peer counselling and support for women, and specific peer support for women who use injecting drugs – must be funded. Testing, including pre- and post-testing counselling and support, must take into account the particular issues for women who are diagnosed with HIV.

2. Medical care and HIV treatment

2.1 Universal precautions

"Universal precautions" are a set of precautions designed to prevent transmission of HIV, hepatitis B (HBV) and other bloodborne pathogens when providing first aid or health care. Under universal precautions, blood and certain body fluids of all patients – not just those known to be HIV positive – are considered potentially infectious for HIV, HBV and other bloodborne pathogens⁶. We are concerned at the apparent lack of knowledge of universal precautions in some settings:

"I still have yellow 'danger of infection' stickers on all my blood forms, despite the fact that I know this is against World Health Organization guidelines. And this is in a major teaching hospital. It makes me feel so dehumanized."

PozFem UK member, January 2008

2.2 Health workers' understandings of risk, responsibility and confidentiality

An HIV positive woman suffering from a life-threatening haemorrhage following a miscarriage recalls her experience at A&E:

"I disclosed my status on arrival at the Accident and Emergency to make the staff aware so that they could take precautions, not only for their safety but for my own. In the recovery room, I woke up to find everyone was looking at me like I was an alien. I knew they knew I was HIV positive. I was in pain and I did not really care much, but the nurses would not come anywhere near my bed. When they came I would just hear references to 'she' and the rest they would mime. It was obvious: She is HIV positive. They wore doubled gloves and doubled aprons as if my blood was shooting out of a hose pipe at them. I just looked on, I couldn't wait to get out of there to go home. I was only in hospital for two days, but it seemed twenty years."

Anon, Positively Women Magazine, Winter 2007

An HIV positive woman who provides one-to-one emotional support to HIV positive women in prison says:

"I met this girl in prison. She was only 22 years old, a drug user and homeless. She had been diagnosed with HIV and HCV (Hepatitis C) for only one week and she also had a terrible infection in her legs because of injecting in the groin. If the infection progressed her legs may be amputated. She disclosed her status to a nurse that was meant to do the dressing for the infection on her legs and the nurse

refused to do the dressing because she feared to be infected with HIV. This happened in January 2008, not twenty years ago! "

PozFem UK member, January 2008

PozFem UK members raised the issue of potentially discriminatory practices in dentists' surgeries, and their lack of application of universal precautions:

"I went to the dentist in March 2007. Having given me a check up, the dentist then questioned me about how long I had been diagnosed and how I came to find out my status. She then asked if I knew what the transmission route of my HIV was, like this would somehow be helpful to my treatment, rather than for her to make her own personal judgments. This was all done with the dental nurse present and within easy hearing distance of the reception."

PozFem UK member, January 2008

"I and many women in my group have experienced that when we go to the dentist we are always made to wait till we are last in the queue, in case of infecting others. But how do they know that no-one else has HIV – or something more infectious than HIV?"

PozFem UK member, January 2008

We recommend increased training for health workers in universal precautions, the right to health, privacy and confidentiality.

2.3 Treatment for all?

The UK Government's commitment to ensuring Universal Access to Treatment for people in less economically developed countries is well-known. Less well-known is the lack of Universal Access to Treatment in the UK.

While most people living with HIV in the UK are able to access free treatment, there are certain groups who, at the time of this meeting, were denied ongoing access to treatment (notably failed

asylum seekers), or expected to pay for their treatment (visitors). An additional complication for failed asylum seekers is the fear of detention if they try to access services, including health care, and the trauma of possible deportation to countries where there is limited access to treatment.

“My partner came to the UK as a visitor and fell ill and was hospitalized. He comes from an economically poor country and didn’t have travel insurance. Even though he was tested negative in his home country for TB and HIV he was diagnosed as being HIV positive and having HIV-related TB within weeks of being in the UK. This was a huge shock for him and me. He began to be charged hospital fees.

We were homeless and had many other problems so my partner just took the hospital bills to his legal aid lawyer and we tried to forget about them. However when he had to leave the UK, he got chased relentlessly in his home country so that when he applied to come back to the UK, the NHS debt collectors wrote to the British Embassy in his country and his application was refused. We later paid for a good lawyer who said that my partner had been treated unlawfully.

He was eventually granted leave to stay in the UK and returned. He started being chased again by the NHS debt collectors... My partner was threatened with court action and embarrassment. We finally negotiated to have him pay £40 a month towards his £10,000 plus debt.”

PozFem UK member, January 2008

“The Home Office seems to be making decisions on applications without telling applicants or their lawyers. Applicants then suddenly get arrested and detained as they have missed their rights of appeal. This is particularly awful for people living with HIV who suddenly find themselves not only detained but with no medication. Sometimes their friends or family don’t even know where they are

and those arrested are not able to make phone calls, the police now do it on their behalf. Sometimes they get bundled away in the night after they have been arrested and their friends or family have to drive hours to get them their medication. A friend only had two weeks medication supply and was due to be deported. She saw the doctor at the detention centre who said it was not the UK’s responsibility to provide more than three days worth of medication should she be deported! One of the drugs she takes is not available in her home country and she is already resistant to many ARV’s.”

PozFem UK member, January 2008



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Angelina

The public health benefits of ensuring access to HIV treatment, care and support for all in the UK who need it, regardless of their status, are clear – as is the duty to ensure the right to the highest attainable standard of health.

We are pleased to see recently (and since our consultation meeting) some tentative steps in the right direction towards policy changes in England and Wales to provide treatment for all who need it in the UK.



Adrienne

3. HIV positive women and the workplace

3.1 HIV positive women working in the health sector

We are concerned at an apparent lack of Department of Health and NHS public support for and solidarity with HIV positive NHS employees, and the lack of institutional support for HIV positive workers in the private health and social care sectors.

“The news frequently reports scares because an HIV positive worker has put patients at risk. However it is perfectly safe for HIV positive people to work in most health departments. Many nurses and other health staff have been recruited to work here for the NHS from countries of high prevalence. If they are HIV positive they need more open support. They are contributing to our health system with their work, they are not a threat.”

PozFem UK member, January 2008

“I was working as a psychiatric nurse and we had an HIV positive patient. The nurses working with me were really worried about looking after him, and they

made some really negative comments...It made me feel so scared...What if they knew about me? I just couldn't be open about my status at work.”

PozFem UK member, January 2008

We would welcome the adoption of strong workplace policies on HIV/AIDS and zero tolerance of HIV-related discrimination in the health sector to ensure the contribution of people living with HIV is valued, and the working environment is one in which people who choose to be open about their status may comfortably do so without fear of discrimination.

3.2 HIV positive women in the education sector

In 2007, UNESCO released a report entitled *“Supporting HIV-positive teachers in East and Southern Africa”*. This was based on a technical consultation with many stakeholders, including networks of teachers living with HIV. In its conclusion the report states: *...just like anyone else, teachers are vulnerable to HIV infection and may be personally affected by HIV in their families and communities. Those living with HIV may be unwilling to disclose their status due to fear of discrimination, unfair treatment, or loss of employment. The education sector has the responsibility to support all teachers, regardless of their HIV status, and to demonstrate zero tolerance towards acts of HIV-related discrimination.”*

The report goes on to outline ways in which teachers can be supported:

- identify the needs and impact on teachers living with HIV;
- ensure access to prevention programmes, treatment, care and support;
- provide support for teachers by teachers;
- developing partnerships between HIV-positive teachers' networks and teachers' unions;

- HIV and AIDS workplace policies for the education sector;
- strategic partnerships, including with school administrators and other sectors⁶.

PozFem UK is concerned at the apparent lack of public support and solidarity with HIV positive teachers and schools staff on the part of the Department for Schools Children and Families (DCFS). We recommend the adoption of UNESCO's conclusion and recommendations for supporting teachers in the UK.

3.3 Asylum and the right to work

PozFem UK is concerned at the existence of HIV positive women asylum seekers who are imprisoned for working without papers.

"I am here because I was working, trying to pay my rent and send money home to my family to keep my children in school. I was sentenced to 8 months imprisonment, and now even if my sentence is finished I am still in prison because they want to move me to a detention centre to deport me. Here in prison I see people who could work but who go and pickpocket and get two weeks and then come out. But I was working and after 8 months I am still here treated like a criminal. Is this justice?"

Anon, Personal communication to Positively Women prison outreach worker, January 2008

Often women in this situation receive their HIV diagnosis in prison, and may be faced with breaches of confidentiality, bullying and other mistreatment. They are often detained beyond the end of their sentence, awaiting deportation. PozFem UK wishes to highlight the particular consequences for HIV positive women of the rules concerning asylum seekers and the right to work.

4. Attitudes to people living with HIV

Whilst enormous strides forward have been made in understanding HIV and providing treatments which suppress it, the same cannot be said for levels of awareness. In some instances, it seems as though backward steps are being taken or that time has stood still as more and more of us report facing ignorance and prejudice in workplaces, schools, churches and healthcare facilities. Information provision and education play a key role in increasing awareness about HIV and addressing negative attitudes, especially when it is provided by women living with HIV.

4.1 Attitudes in schools

The challenges facing HIV positive children in schools are significant. The following is a recent experience of a Positively Women service user's child in a school in the UK:

"My school does know about my HIV status and they have treated me very badly. Once when I had a cold sore they locked me in a room for four hours because my mum and dad couldn't come and collect me, they thought I would give HIV to the other students, they also watch me all the time. My mum was very angry with the school and I think she rang up to shout at them."

James, Positively Women Magazine, Summer 2007

Privacy and confidentiality are clearly ongoing issues for HIV positive children in schools.

"My daughter is training to be a primary school teacher and some of her fellow students think that if a child in school is HIV positive that everyone should know. This is against their human rights."

PozFem UK member, January 2008

4.2 Attitudes to HIV positive women having children

For HIV positive women, being pregnant can be a very stressful experience.

“Even though it was planned when we already knew I was positive, we still felt anxiety about the outcome for my baby – but it was much better that I was dealing with this without the shock of diagnosis at the same time – and that my partner is wholly supportive. Our lovely daughter is negative and is now happy and healthy and at primary school.”

PozFem UK member, January 2008

Although HIV positive women in the UK have less than a 2% chance of passing HIV to their babies when the standard precautions are taken to reduce mother to child transmission, many people still see HIV positive women willing to have children as selfish women who potentially put their children's lives at risk. For HIV positive women injecting drug users having children, judgemental attitudes are particularly prevalent. While many health workers and medical professionals are extremely supportive of HIV positive women's rights and decisions, there are instances of less positive attitudes.

“When I first arrived in London I found at last the courage to ask a consultant if I could have a baby. I was going through a really hard time dealing with my diagnosis and was really depressed. The doctor took her glasses off and looked at me without saying anything for a few instants. Her expression made me feel really bad, like she was saying: ‘Why do you want to bring also this upon yourself? Don't you have enough to worry about?’ She explained in a very monotone voice about mother to child transmission and how to avoid passing HIV to the baby, but I could feel she was disapproving. So for years I just put it out of my mind. Now I am too old.”

PozFem UK member, January 2008

Negative attitudes may also be shown towards HIV positive mothers by others living with HIV.

“I felt that it was important that women with HIV no longer lived under the misapprehension that they couldn't have children or, in some of the most harrowing cases, be persuaded by GPs to terminate their pregnancies. So I got my kit off on the cover of Positive Nation magazine with a massive pregnancy bump and upbeat attitude. I certainly received positive feedback from women living with HIV, but was startled by some of the vitriolic abuse I received from a minority of gay men. I was accused online of being disgusting, promoting the spread of HIV and failing to protect my children who would either catch HIV or be scarred by society inevitably lambasting them for having a mother with that ‘disgusting disease’.”

Susan, Positively Women Magazine, Spring 2006

HIV positive women, including HIV positive lesbians, hoping to access assisted conception services (such as IUI or IVF) often face major hurdles. An HIV positive woman in a discordant heterosexual relationship reports:

“Eventually I started to make enquiries about going to the fertility clinic. It looked like there were going to be problems being taken on by a clinic as an NHS patient and as an HIV patient. There are borough restrictions and because of the HIV there was a waiting list. As for private clinics, I didn't even know if they would take someone who is positive [...]. [Eventually I found] a particular borough that offers you three rounds of treatment (intrauterine insemination). What happens after that we haven't really discussed. I can not have IVF in this clinic because I am HIV positive [...]. If this doesn't work we have to go back to the catheter and the syringe or we have to do what a lot of people do and have unprotected sex.”

Sofia, Positively Women Magazine Summer 2006



Alice

We believe that more training opportunities in psychosocial aspects of HIV should be provided for medical staff, health visitors, midwives and others involved in ante- and post-natal support to women. We are concerned that the sexual and reproductive rights of HIV positive women should be a specific focus of training.

PozFem UK recommends that HIV positive women, including HIV positive lesbians, should not face discrimination in accessing assisted conception services such as IUI and IVF.

We call for greater awareness-raising among health professionals and wider society of the fact that safer childbirth options result in a very low risk (less than 2%) of mother to child transmission of HIV. We also call for the development of a culture of respect for and upholding of the sexual and reproductive rights of HIV positive women, including the right to have children.

4.3 Aging and HIV

The number of older people living with HIV has been steadily growing. In 1997,

there were only 50 older HIV positive women over 55 accessing care. In 2006, as a result of successful treatments reducing the number of premature deaths, there were 603. However, PozFem UK members were concerned that there is a lack of research and awareness generally about the issues which face older women living with HIV, which include managing long term side effects; dealing with HIV and the menopause; and the impact of growing older with HIV. We would like to see further research on the health issues of women living long-term with HIV, Hepatitis C co-infection and drug use, and on the effects of drug use on HIV and antiretroviral treatment.

5. General awareness of HIV and Sexually Transmitted Infections (STIs)

According to the Health Protection Agency, the annual number of new diagnoses has increased by 182% over the past 10 years⁷. Among young people, it is clear that prevention messages and information around risks of transmission are not reaching the larger population, and many people remain unaware of the links between alcohol consumption, violence, unsafe sex, high teenage pregnancy rates and the transmission of HIV and STIs.

Awareness of the impact of STIs on sexual health, fertility and vulnerability to HIV is also very low among the general population and especially youth: 89% of young people rarely or never worry about HIV, despite recent statistics showing that 11% of young people have Chlamydia, and a surge in other STIs among young people.

We are concerned at the failure of prevention messages in raising awareness, and the fact that this is related to the lack of strong support for and public solidarity with women and men living with HIV.

6. HIV and violence against women

Many studies around the world have shown that there is a strong link between the inferior position of women in society, heavy drinking, domestic violence and HIV. Domestic violence is a reality for many women with HIV before and after their diagnosis:

“A woman from my group told her partner immediately after she got diagnosed... he pushed her with her head inside the toilet and flushed it...”
PozFem UK member, January 2008

“I found it hard to cope with HIV; I attempted suicide on more than a few occasions. I really thought there was no hope for me [...] My marriage was an abusive one. I remember after one fight in particular when he had tried to strangle me, the neighbours called the police and they took me to the hospital. After almost three years the level of abuse was too much and I became homeless...”
Macey, Positively Women Magazine, Spring 2007



Memory

In the UK, two women are killed each week as a consequence of domestic violence and one in four women will experience domestic violence in their lifetime. This includes psychological, sexual, emotional, financial and physical abuse and it is against this backdrop that we must address women's capacity to protect themselves. However, within the National Strategy there are no points concerning gender violence and HIV.

HIV does not happen in isolation. It is strongly linked to violence against women, lack of knowledge, poverty, social and economic exclusion, homelessness, child poverty, statelessness, and other types of marginalisation. Any response to HIV, including the National Strategy for Sexual Health and HIV, needs to take a gendered approach, and address the social, economic and political context in which the epidemic is taking place.

7. Criminalising HIV transmission

When the National Strategy was drafted in 2001, criminal prosecution related to HIV was not such a concern as it is today. We are concerned at the growing trend to criminalise people living with HIV, including through prosecution for transmission of the virus. For more information on criminalisation see ICW News 40, and ICW's criminalisation paper on <http://www.icw.org/node/354>

Here are the words of a woman convicted and imprisoned for transmitting HIV:

“I feel now that through this experience I am left feeling like a criminal for being HIV positive and my fear is that now people won't be tested through fear of prosecution about being positive [...] to be where I am today, in prison. I am learning how to live a criminal life. I am unable to talk to my son. I wake up every day on edge, waiting for someone to

discriminate against me for being who I am. I am petrified of coming out. I fear reprisal attacks."

Sarah, Positively Women Magazine, Autumn 2006

A woman whose husband was convicted for transmitting HIV to several women comments:

"I do thank God that he cannot carry on doing what he was doing. People say it takes two to tango, Yes, it does. But the way I look at it is: I married him. He didn't give me the choice. You know if you have a one night stand, you should take precautions. But at the same time some people with HIV know their diagnosis and they should be responsible; maybe a little more responsible and they should practice safe sex. But in a marriage I don't see how that works, unless the person is honest from day one."

Jeanette, Positively Women Magazine, Winter 2006

PozFem UK members believe it is important that information, training, policies and laws are developed to deal with transmission of HIV in a way that promotes responsibility and solidarity, but does not reinforce stigma. In general circumstances, PozFem UK believes that legislation to criminalise HIV transmission is not the best way to do this.

8. Lack of awareness of the GIPA principle (Greater Involvement of People living with HIV/AIDS)

The principle of Greater Involvement of People living with HIV and AIDS (GIPA) was enshrined in the 1994 Paris Declaration, but implementation of this principle has been limited⁸. Women living with HIV have a wealth of expertise and knowledge to contribute, particularly in relation to issues affecting our lives; and in the development of policies and projects which impact on us. Our involvement in public consultations will result in policies and strategies grounded in the reality of

our lives. However, involvement must be **meaningful**. Consultation meetings **must** be organised with more than a few weeks' notice, to enable us to prepare for the meeting. Meaningful involvement should not be seen as merely the participation of HIV positive women in official consultations. Funding **must** be provided to allow HIV positive women to organise, to set up our own meetings (including pre-meetings before official consultations), and to monitor the implementation of policies and strategies and their impact on our experience of living with HIV.

9. PozFem UK's recommendations

The sections above contain a number of specific recommendations. In addition, we set out below our wider recommendations regarding the response to HIV and AIDS in the UK:

We recommend:

- A human rights agenda, in line with international agreements signed by the UK government.
- An integrated government-wide response to HIV and AIDS.
- A holistic view of health care, including physical, psychological, sexual, and material well-being, with provision of integrated sexual and reproductive health services all in one place.
- A National Strategy for Sexual Health and HIV which is gendered, in line with UK law.

We also recommend the following actions for change:

Employment:

- The promotion of workplace policies and practices (within the health and education sectors and beyond) which ensure and uphold the rights of all women with HIV to work, to job retention, promotion, training and recruitment, irrespective of HIV status.

Access to care, treatment and support:

- The adoption of a national policy that promotes universal access to care, treatment and support for all those living with HIV in the UK, including failed asylum seekers, and which addresses policies that hinder this.
- The implementation of Universal Access to Treatment and Universal Precautionary Principles, as set out by WHO and UNAIDS.

Information and education:

- The promotion of the universal role of education and edutainment to promote HIV awareness and prevention, and solidarity, care, inclusion and support for those of us with HIV, including respect for our human rights.

Partnership:

- The promotion of partnerships and collaboration between PozFem UK, government, and the voluntary, educational, private, business and faith-based sectors.

Diversity:

- The development of an HIV and AIDS policy which promotes and celebrates diversity – and challenges the root causes of stigma which focus on blaming those most marginalised in society, through homophobia, gender inequities, racism, religious fundamentalism, and prejudice against people who use drugs, people in prison, people without homes, people from abroad and others marginalised by society.

We call for all involved in the response to HIV and AIDS in the UK to include and consult with PozFem UK, ICW and Positively Women, to build an effective, integrated, realistic, attainable and sustainable strategy.

Nothing about us without us



Carmen

PozFem UK's evolution

Since 2005, PozFem UK has supported, trained and mentored 25 Regional Coordinators from England, Wales, Northern Ireland and Scotland. Through 6 training sessions Coordinators have created a strategic plan for the development and sustainability of the network. All reported increased skills - especially around public speaking, peer support and influencing policy. All sessions were facilitated by HIV positive women. This is how one of the participants commented on the training session on public speaking held in Swansea in October 2007.

“...I really enjoyed meeting other positive women and hearing their inspiring stories and how they are dealing with the difficulties of living with HIV. The training...both enlightened and empowered me and will lead to me being able to put my newly acquired skills to good use in order to raise awareness.”

Regional Coordinators all have strong links to their local groups where they share and feed back what they gain at PozFem UK. They also use PozFem UK to discuss their regional problems and possible solutions

PozFem UK key outcomes to date:

- Increased input in local, national and international policy consultation
- Increased involvement with the media: newspapers, radio and TV
- Increased talks in the community including churches and schools

Source:

- ¹ *Better prevention, better services, better sexual health: The national strategy for sexual health and HIV*, 2001, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133
- ² *Why sexual health is a cross governmental issue*, Independent advisory Group on Sexual Health and HIV, Annual Report 2006/7
- ³ *Key facts by region: 2007 AIDS Epidemic Update*, UNAIDS, available at http://data.unaids.org/pub/EPISlides/2007/071118_epi_regional%20factsheet_en.pdf
- ⁴ *A complex picture: HIV and other Sexually Transmitted Infections in the UK: 2006*, Health Protection Agency
- ⁵ Universal precautions, defined by the Centers for Disease Control and Prevention (CDC), see http://www.cdc.gov/ncidod/dhgp/bp_universal_precautions.html
- ⁶ *Supporting HIV-positive teachers in East and Southern Africa: technical consultation report*, UNESCO, 2007
- ⁷ *Testing Times: HIV and other Sexually Transmitted Infections in the UK: 2007*, Health Protection Agency
- ⁸ For more information on GIPA, see: <http://www.unaids.org/en/PolicyAndPractice/GIPA/default.asp>
<http://www.icw.org/node/136>

See also:

Alice Welbourn

<http://www.disabilitynow.org.uk/have-your-say/guest-column/becoming-positively-human>

Doyal and Anderson, OXFAM Gender and HIV Reader, 2008, Chapter 8:
<http://publications.oxfam.org.uk/oxfam/display.asp?K=e2007042416491709>

ICW Vision Paper 6: HIV positive women and drug and alcohol use, 2007, and Silent Voices report, ICW.

Alice Welbourn,

http://www.opendemocracy.net/article/5050/international_womens_day/hiv_aids

ICW Briefing Papers:

Violence against Women

<http://www.icw.org/files/VAW-ICW%20fact%20sheet-06.doc>

Sexual and Reproductive Health Rights

<http://www.icw.org/files/SRHR-ICW%20fact%20sheet-06.doc>

Access to Care Treatment and Support

http://www.icw.org/files/ACTS-ICW%20fact%20sheet-06_0.doc

PozFem UK is the only national network of women living with HIV. It was established during Changing Tomorrow, the UK conference of people living with HIV, held in Leicester in September 2004. PozFem UK works through 20 HIV positive regional coordinators who are linked to regional groups around England, Northern Ireland, Scotland and Wales. The International Community of Women living with HIV/AIDS (ICW) and Positively Women provide technical support to PozFem UK. PozFem UK is an initiative that is funded by The Big Lottery Fund.

Web: www.poz-fem-uk.org

This vision paper has been produced by The International Community of Women Living with HIV/AIDS, in partnership with PozFem UK and Positively Women. It came about as a result of PozFem UK's involvement in the National Strategy for sexual health and HIV review, and accompanies our formal input to that process. However, it has far wider relevance. It documents concerns and recommendations raised by members of PozFem UK, on the basis of our personal experiences. We hope it will serve as a useful advocacy tool for HIV positive women around the UK.

The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development.

All HIV positive women can join ICW for free. Just contact us at:

International Community of Women Living with HIV/AIDS (ICW)

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ICW is registered in the UK as a company limited by guarantee with charitable status.
Company No 2987247
Registered charity No 1045331

Positively Women is the only national charity for women and families living with HIV in the UK. The organisation provides practical and emotional support; enables women to make informed decisions about health and personal choices, and challenges stigma and discrimination. Established 21 years ago by two women living with HIV determined to address the lack of services available for women; today Positively Women remains strongly committed to the ethos of peer support and empowerment. Services include guidance, advice and advocacy; outreach work in hospitals, clinics and prisons; information services; support to children and families; skills building programmes; as well as campaigning activities.

Positively Women

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