



## HIV Positive Women, Pregnancy and Motherhood

### ICW<sup>1</sup> submission to the UK All Party Parliamentary Group on Population Development and Reproductive Health hearings on maternal morbidity

#### Summary<sup>2</sup>

Despite HIV positive women having the right to make informed voluntary decisions about having children or not and the right to healthy motherhood, in practice it is hard to achieve our reproductive rights and hence ensure full reproductive health. Testimonies shared by ICW members, all of whom are HIV positive women from around the world, show that those who choose not to have (more) children struggle to access appropriate contraceptives and related services. Negotiating their use with sexual partners can also be difficult. A decision not to have children is, amongst other reasons, influenced by negative social reactions to HIV positive women having children. In fact when HIV positive women want to get pregnant or are pregnant they often face a lack of services and information about how to safely conceive, have a healthy pregnancy and look after a baby. This situation is exacerbated by severe discrimination by health care workers, communities, the media, politicians and even HIV activists, against HIV positive women who wish to be or become pregnant.

The emphasis on HIV testing in antenatal clinics serves to reinforce the belief that women bring the virus into the family, at a time when they are struggling with the trauma of their status and the impact on both their unborn and their older children. The failure of testing services to consider the discrimination and gender inequalities HIV positive women face on disclosure of their status lead many not to disclose. Not disclosing, or the stigma and discrimination if they do, then prevents women from accessing appropriate care, treatment and support, or testing services, for themselves and their children. Badly-designed services and indiscreet health workers that do not protect confidentiality and badly-designed policies, such as those criminalising HIV transmission, put not only HIV positive women's reproductive rights at risk, but also endanger their rights to the benefits of scientific progress, health, liberty and life.

Some good examples of support for HIV positive mothers, training for health workers etc do exist. To ensure they are the norm requires commitment from policymakers, health managers, NGOs, community leaders and activists. Together we need to ensure that HIV positive women are provided with non-judgemental, confidential support, services and advice on contraceptives, conceiving, child bearing and rearing, that will enable them to make informed decisions about whether to have children (or not) and how to rear them. We also call for meaningful involvement of HIV positive women in the design of policies and programmes in order to ensure they are relevant to our lives.

<sup>1</sup> ICW is the only international network of HIV positive women with more than 7000 members in 120 countries. A key aspect of our work is to promote the reproductive rights of HIV positive women around the world.

<sup>2</sup> ICW uses the first and third person in this document in order to reflect both the personal voices of our members while at the same time recognising the diversity of our experiences as HIV positive women. ICW would like to thank all ICW members that contributed to this briefing.

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

**HIV positive women face a range of dilemmas and discrimination, particularly in relationship to pregnancy and motherhood. This article is a collation of the global experiences of ICW members, described in relation to a human rights framework. Through this submission ICW hopes to bring to the Hearings the voices of HIV positive women who experience the brunt of HIV and reproductive health policies and programmes or the lack of them. At ICW we firmly believe that if these voices are not heard then inappropriate policies and programmes will result. We also make recommendations to policy makers and programmers so that together we can uphold HIV positive women's reproductive rights.**

A founding declaration on reproductive rights and health is the United Nations International Conference on Population and Development (ICPD) declaration and Programme of Action, which emanated from that conference in Cairo in 1994. It goes beyond health issues and enshrines a number of rights including: the right to decide freely on all aspects of sexuality and reproduction and to live free from violence and coercion. Although important, this declaration is not specific to HIV positive women.

In a Charter created by young HIV positive Swazi women, the section on reproductive rights (box 1) illustrates that 1) HIV positive women share the same rights as other women and that 2) Some rights can only be fulfilled for HIV positive women if specific measures are put in place, such as access to prevention of mother-to-child transmission (PMTCT) services; information about, and consideration of, the impacts of anti-retroviral treatment (ART) on our bodies and lives; information and services to support healthy sex lives and safer conception; and information on infant feeding.

Yet in practice it is hard for HIV positive woman to fulfil their reproductive rights as divergent ideas about who should and who should not have children can leave women caught between the pressure from health workers not to have children and family pressures to have children. Decisions around child bearing and rearing are based on many factors, including a woman's desire to have a child, pressures from family members, advice and/or directives from health care workers, cultural ideas about the family and also wider community and media reactions to HIV positive women who have children. Having children is also an important source of identity as an adult in many societies, and of security in old age.

### **Making decisions not to have children**

ICW research shows that women who already have children when they are diagnosed as HIV positive often feel they do not want to have more, while those without children are more likely to want children or to feel pressured into having them. However, lack of access to appropriate contraceptives, and little control over decisions on child-bearing often lead to unplanned pregnancies and considerable anxiety about the health of unborn children. For women who decide to terminate a pregnancy, lack of access to safe, legal abortion compromises their health. HIV positive women who choose to have an abortion often do so because of fears that they will not be able to raise the child due to poor health, that pregnancy will lead to a deterioration of their health, that their babies might contract HIV or be unhealthy and because of the discrimination that mother and child are likely to face.

*"When I lived with him, I got pregnant. I decided on my own to have the abortion and get sterilised at the same time at a hospital. I did that because I had the infection."* (ICW member, Thailand)

### **Box 1 – Reproductive Rights: HIV positive women have the right to...**

- decide whether and when to conceive without being judged
  - decide on the number and spacing of children
  - abortion or sterilisation on demand, (without requiring the consent of another person)<sup>3</sup>
  - keep the baby
  - education on reproductive health options (labour, delivery, breast feeding and PMTCT)
  - access quality ante-natal care (with or without being accompanied by a partner)
  - equal access to reproductive health care, regardless of social, economic or political status
  - family planning information and decision making over the type and use of contraception
  - access preventative methods of contraception such as microbicides
  - safe delivery, how and where we want
  - assisted conception or artificial insemination
  - feed the baby the way we want (and accurate information about feeding options to be able to make an informed decision)
  - prevention of mother-to-child transmission (PMTCT) services
- (ICW Young Women's Dialogue, Swaziland 2004)

Sadly the lack of appropriate treatment and care for HIV positive mothers and their children and the often negative wider societal reactions (including from health care workers) to HIV positive women wanting to have children can powerfully influence women's decisions about whether to have children or not.

<sup>3</sup> ICW also advocates for the right of HIV positive women not to be coerced into sterilisation or abortion.

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### **Making decisions to have children**

Although there are positive women who choose not to have children, many, especially those who are not yet mothers, want to become pregnant and have a family, particularly given the advances in treatment, which translate into longevity of the woman and the greatly increased likelihood that she can give birth to an HIV negative child. For many women, having children is an important part of claiming a full and fulfilling life. HIV positive women should not and need not be excluded from this aspect of life.

*"This is my first pregnancy. I would really love to have a child."* (ICW member, Zimbabwe)

Some women are pressured by family or societal norms into having children. For example, women are often not seen as 'full' or 'proper' adults until they have children. Having children generally gives women a higher social status, whereas women who do not have children may be stigmatised.

*"If you don't have children you are less of a woman. You lose everything even your inheritance."  
I have five children and am expected to have another because I do not have a son."* (ICW members)

Decisions around motherhood throw into sharp relief unequal power dynamics in personal relationships and cultural expectations about marriage. For an HIV positive woman to increase the chances of having a healthy baby it helps to have the cooperation of her sexual partner and this can become yet another battle an HIV positive woman has to fight. An ICW member from South Africa describes her experience:

*"You must be married if you have children. And because I got HIV I did not have time. I was forced to get married to have another child. When I got HIV I only heard you are going to die and can not have children and my mother told me it's a sin to have a child. Because they know I have HIV they [neighbours] start to create stories. My husband he came to tell me that if you have a child it will have HIV. We have gone through everything and now he is starting to doubt every decision. He started to believe what was on the street. He thinks I am going to die of HIV."* (ICW member)

Whether positive women want to have children or find themselves pressured into becoming mothers, they face varying degrees of advice and support.

*"The nurses advised me not to have any children again. I gave birth two years later but my husband became ill and died of HIV/AIDS in the same year. The nurses shouted at me why I did not listen to their advice. I had her because I wanted a child in my life."* (ICW member, Zimbabwe)

Unfortunately, HIV positive women are rarely told about assisted and safer conception methods, how to protect their health during pregnancy or how to reduce mother-to-child transmission particularly after the birth. This can be due to a lack of available services or a lack of information but it can also be due to discrimination against HIV positive women wishing to become pregnant or who are pregnant. Without a consideration of the woman's health and socio-economic circumstances any positive effects of PMTCT treatment can be reversed.

*"You are only important when you get pregnant, the baby becomes important. Once you are separated you have to see to yourself."* (ICW member, South Africa)

However, positive women do sometimes receive good care and sympathetic treatment during pregnancy and motherhood. Having information about healthy motherhood can also put women in a much stronger position.

*"If it is something you are longing for you have to go ahead. You can have a healthy birth if you make enough research – that is what I am going to do. This helps, then it is easy to tell the doctor – if you say I know what I want, they listen."* (ICW member, South Africa)

### **Discrimination and the impact on our choices**

In many health care settings HIV positive women face considerable discrimination and are not given the chance to make fully informed decisions (see ICW materials and references listed below). Our members have reported being denied access to information about PMTCT, termination of pregnancy and sterilisation services when they want them, but have also experienced undue coercion to undergo sterilisation and access contraception. Several of our members have reported that they have been told they must have a Depo-Provera injection before being given ART.

*"We should decide to keep the baby or to terminate. But they don't give you the option. They sterilise you. You feel obliged to take the option they offer you or you feel you can't take the immediate service you need."*

*"I went to clinic for counselling and abortion. They said why don't you sterilise because you will have an HIV positive child and because of your condition. Your health will deteriorate."*

*"I went to the hospital to be sterilised. They wanted the husband's consent, but he wouldn't as he did not have a boy child."* (ICW members, South Africa)

Young HIV positive women, migrants, lesbians, sex workers, injecting drug users and women with other disabilities also are likely to face even greater degrees of stigma and discrimination; the range of advice and services available are even more constrained. Given the potential discrimination faced by HIV positive women within health care services it is not surprising that some women choose not to disclose their status. This in turn makes seeking

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appropriate care and services even more problematic. Indiscreet staff in the health system or services designed in a way that reveal a woman's status to others can cause untold psychological trauma and leave her vulnerable to abuse.

ICW trainings with health workers show that health workers tend to be more sympathetic to women's decisions and situation if they have been through trainings or sensitisations conducted by (and with) HIV positive women. Other initiatives, such as the Mamas Club in Uganda, show the transforming impact of a safe, non-judgemental environment, advice and support run *by* and *for* HIV positive mothers.

The rights of HIV positive women who get pregnant are also often compromised by judgemental attitudes beyond health services, in communities and elsewhere. HIV positive women who have children can face being excluded from support groups, losing jobs or being labelled as irresponsible, selfish or even murderers even by representatives of HIV organisations. This is particularly true for women who are more marginalised in society, such as injecting drug users and sex workers. Public officials and others who judge us and speak on our behalf create an environment that stigmatises us and limits our choices about our reproductive lives.

*"We have organisations but men lead the organisations and our issues don't get discussed."*

*"Policymakers sit in board rooms and decide what is relevant to our lives – we are not part of the process.' There is always a male AIDS activist labelling us as murderers and selfish. They are the ones responding to programmes on the TV and radio about HIV positive women and pregnancy. An AIDS activist on the radio was asked about HIV positive women having babies. He doesn't feel it is their right yet he has two."*  
(ICW members, South Africa)

The worrying trend in some countries to criminalise HIV positive women for transmitting the virus to their children will only serve to exacerbate stigma and discrimination against us, and discourage women from testing and seek appropriate care, treatment and support. Such laws are unfair not just because HIV positive women may be unable to avoid getting pregnant but also because it is a fundamental right of *all* women to make decisions about whether (and when) to have children. (See [www.icw.org/node/354](http://www.icw.org/node/354) for resources on the impact of criminalisation on women).

### HIV testing in antenatal clinics (ANCs)

*"When I was pregnant and went for antenatal care, I was told to have a blood test. They did not tell me what the test was for. Every woman who came to the clinic had to have their blood tested. I realised it was the AIDS test when I received the results."* (ICW member, Thailand)

Antenatal clinics constitute an important way of reaching women and supporting their sexual and reproductive health when they may have limited access to other treatment and support services. However, outside antenatal care, testing for women is often neglected, for example, through workplace testing programmes. Focusing on ANCs may leave women who are not pregnant, or who do not have access to ante-natal services, out of the picture.

Testing in ANCs can also reinforce the mistaken view that it is women who bring HIV into the family, shifting responsibility away from men to get tested and disclose to partners. Receiving an HIV positive diagnosis during pregnancy is traumatic, particularly if informed consent has not been given. Often testing is done with total disregard as to how a positive diagnosis can result in severe discrimination from a woman's family as well as feelings of self-worthlessness. A recent study showed that more than two-thirds of HIV positive women in South Africa, who tested HIV positive when pregnant, did not disclose their status for fear of reprisals from community, partners or family members (Rochat, Stein, Richter 2008). Trying to keep her HIV positive status a secret or the harmful consequences if that status is disclosed can negatively impact on a woman's ability to care for herself and her children. HIV positive women (and men) require more flexibility in the way testing facilities are provided, so that they can make informed choices based on their circumstances. Staff at treatment and testing facilities, including ANCs, need to understand the complexities of women's lives. This would help ensure that the advice and treatment they offer HIV positive women is appropriate and is therefore more likely to enable women to use information about their status to benefit themselves and their families.

### Breastfeeding

Evidence indicates that either exclusive breastfeeding or exclusive feeding with milk-alternatives, rather than mixed feeding, is effective in reducing mother-to-child transmission of HIV. However, HIV positive women rarely receive correct information about feeding options and alternatives to breast milk, or advice about complications such as sores in the baby's mouth or breast inflammation. The cost of alternative sources of milk puts this choice out of the reach of many women. Decisions to breastfeed are often based on HIV-related stigma associated with women who do not breastfeed and cultural ideas concerning what behaviour constitutes 'proper motherhood'. Even when women know the potential risks associated with breastfeeding, they may fear that not to do so will provoke comment among neighbours.

*"In my case the thing that is stigmatised is going to fetch the milk each and every week. It is collected from a particular room and if you go to that room they know you are HIV positive."* (ICW member, Swaziland)

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### Psychological impact on mothers and children

A recent WHO study (2007) from Uganda shows that more than 50 per cent of children with HIV will die before their second birthday (referenced in Musinguzi 2008). What we must consider is the immense stress and heartbreak felt by the children's mothers and the need for them also to receive high quality and on-going care, treatment and support from health care providers and communities alike. Many HIV positive mothers also experience extreme psychological stress over what will happen to their children if they themselves die.

As well as worrying about the health and well-being of children, HIV positive mothers feel anxiety about disclosing to children either their own positive status or the positive status of the child. Disclosure to children can be difficult and it takes considerable courage and preparation (Hejoaka 2008).

*"I find it easy to speak in forums, to international meetings and political leaders about living with HIV. However, I found it very hard to speak to my own children. In fact it is one of the hardest things I have ever had to do."* (ICW member)

*"Finally, after worrying and worrying about it, I disclosed my status to my two eldest children. It was such a relief. They totally accept me and understand about my status."* (ICW member, West Africa)

*"I did tell him when he was 12 that he was HIV positive. But then you know its like 'mom, where did I get it from?' Ah, from me!" and it was really painful. I love you so much my son."* (ICW member, UK)

Despite the problems we face in making informed decisions about child bearing and rearing, many HIV positive women have developed strategies to ensure that, when they have children, they flourish. For example, some ICW members are involved in training on how to make wills. This is to ensure that their property gets passed to their children after their death and is not taken by relatives or other members of the community. Others have created memory books together with their children, filled with family stories and photos, to give their children a lasting idea of their parents and a pride in their personal history.

### Recommendations:

- Provide HIV positive women with non-judgemental support, services and advice about conceiving, child bearing and rearing in order to make informed decisions, free from coercion, about whether to have children and how to rear them.
- Provide non-judgemental support, free from pressure or coercion, to HIV positive women who choose *not* to have children, including access to appropriate contraception and safe abortion.
- Protect the employment rights of HIV positive women, for example, maternity leave and job protection on becoming pregnant.
- Promote further research and funding into the effects on acute and chronic maternal and child morbidity and uptake of peri-natal services of ante-natal testing policies and practices
- Reverse harmful legislation which effectively criminalises transmission of HIV in relation to pregnancy, childbirth and breastfeeding (UNAIDS/UNDP 2008)
- Positive women also call for meaningful involvement in the design of policies and programmes that are relevant to their lives, and the right to speak for themselves. Programmes will only support HIV positive women to maintain their health and that of their children if we are actively engaged in developing and implementing them.

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ICW evidence is drawn from a range of ICW workshop and research reports. All are available online at [www.icw.org](http://www.icw.org).

### Other references:

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### Personal testimonies:

ICW would like to suggest that the All Party Parliamentary Group on Population Development and Reproductive Health consider receiving oral testimonials from:

- Dr Lydia Mungherera, Founder and Chair of the Mama's Club in Uganda, which received a Red Ribbon Award at Mexico 2008, in reflection of its excellent work. Dr Mungherera is a medical doctor and also living with HIV. <http://www.womensenews.org/article.cfm/dyn/aid/2835/context/archive>
- Maura Mea, Founder of Hope for Living, Papua New Guinea. Maura is a nurse by profession and member of the International Steering Committee of ICW. She lost two children because of HIV and underwent a forced sterilisation. <http://www.plusnews.org/HOVReport.aspx?ReportId=79697>

Both women are powerful speakers and have much to request of policy makers.

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