# The All Party Parliamentary Group on AIDS Interact Worldwide ActionAid International International Women's Day

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"Women, HIV and Human Rights – the crisis of criminalization"

Presentation by Alice Welbourn PhD

The Salamander Trust

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# Alice Welbourn PhD

### INTRODUCTION

Good afternoon everybody. It's wonderful to take part in this International Women's Day celebration. Thank you for inviting me.

As you've just heard, I'ld just like to stress that I'm not a lawyer, so I don't remotely pretend to be an expert about any of the intricacies of the law, either internationally or here in the UK. So today I'm just highlighting some particular aspects of the chronic social, economic, and medical complexities of this virus, to explain why criminalization in relation to women is such a crisis, both internationally and here in the UK.

# WHY BOTHER WITH CRIMINALISATION OF HIV TRANMISSION?

Surely there are far more pressing issues facing poor women with HIV worldwide? To some extent, you're right of course. In many countries, access of millions of women and their families to the basic essentials - food, water, shelter, warmth, income and peace are fundamentally compromised through extremes of poverty. These then have crucial effects on their basic physical and psychological well-being and basic capacity to cope with illness and death. The chronic stress and phenomenal resilience of millions of women around the world never ceases to humble me. But the added extra about HIV is that, because of global attitudes, positive women's sexual and reproductive health and rights - and now their right to liberty - are also systematically and institutionally being eroded. HIV is like a match to the tinder box of a drought-ridden land, sprinkled with a concentrated lethal concoction of the worst of humanity's shameful prejudices. Attitudes towards sickness, death, racism, sexism, religious fundamentalism, attitudes to "us" and "them" form the fuel of this tinderbox'. As HIV spreads, its flames spread like wildfire, further alienating those who so often have already been cast out by society, through sexual orientation, drug use, sex work, migrant or refugee status or other reasons. People in every country explain HIV away as something highly distasteful which is someone else's fault, nothing to do with themselves. And the UK is no exception to this. As Helena Kennedy has said, a certain "hysteria" and fear of the "other" has encouraged government to "reach for the law" in a vain attempt to "control" the spread of HIV, along similar lines to their "war on terror"i. And as the flames turn into an inferno, some countries, are now sterilizing young positive women, coercing them to sign consent forms when in labour, so that after delivery when they go for contraception, they learn that this is no longer needediii. This dire compulsion of the medical authorities for control over women's sexuality and their reproductive capacity - a hysteria indeed - extends to eradicate any right for these young women over having more children or not - forever. The government doctors responsible make no apologies. One might legitimately argue that there are others here who should face criminal procedures - not these young women.

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# CRIMINALISATION FLIES IN THE FACE OF SCIENCE AND UNDERMINES GOOD PREVENTION – AND TREATMENT STRATEGIES

Let's have some scientific facts.

- 1) If those young women in Southern Africa are given timely treatment, fewer than 2% of babies would be born with HIV. In the UK last year this figure fell to less than 0.1% that's less than 1 in 1,000 births, even with vaginal delivery<sup>iv</sup>.
- 2) Last year a Swiss Study found that if we are stable on treatment, have an undetectable viral load, and no other STIs are present, we have negligible chance of transmitting HIV to others, even without a condom<sup>v</sup>.
- 3) We know that treatment can be rolled out now 3 million out of the 9 million of us who need it are getting it and taking it as responsibly as we can, despite assumptions that we probably couldn't but that is still 6 million too short and many women continue to face many logistic as well as psychological problems with accessing drugs, including having to seek permission and funds from male partners to access services, having their drugs taken from them for use by their partners as soon as they reach home and sometimes being beaten at home even for showing their face at the treatment centre<sup>vi</sup>.
- 4) Violence against women causes HIV and an HIV diagnosis causes violence against women. There are close parallels between police and court attitudes globally to women who are in, or stay in, violent relationships, and attitudes towards women with HIV. And often, sadly, women are other women's worst critics<sup>vii</sup>.
- 5) Love, care, respect and support for anyone with HIV increases our chances of adherence to a relentless life-long drug regime which can, for some, have many side-effects<sup>viii</sup>.

# SO WHAT HAVE THE UN AND OTHERS BEEN DOING?

The UN agencies, the US and others have promoted global guidance, and campaigns such as "Know your epidemic" and "Save the Unborn Child" to promote an "AIDS-free generation ". This all sounds very laudable in the board room. These guidelines were supposed to promote voluntary and confidential testing of pregnant women, with pre- and post-test counselling. But they have resulted in compulsory mass testing of pregnant women are refused access to further ante-natal services. For those who test positive, this becomes public knowledge, they are often treated judgmentally by health staff, branded and ostracized from their communities iii — and then any treatment they do receive actually ceases once their baby is born, with no support or education about breastfeeding viv.

I do believe the UN agencies did not intentionally plan that human rights be ignored in the process. However this is how many states have interpreted these global guidance documents. At best the consequences are deeply tragic for millions of women, their families and communities. At worst they amount to serious travesties of human rights, for which governments now need to be held to account.

## AND THEN ALONG CAME CRIMINALISATION.

As states were becoming increasingly desperate to curb the spread of HIV, a US-backed initiative launched the Model AIDS Law in West Africa. Thus in Sierra Leone now, for example, if a woman transmits HIV to her child, she can be fined or jailed up to 7 years or both<sup>xv</sup>. Let's examine this more closely:

o where is the guarantee for a woman of access to condoms for prevention, of access to negotiation skills to use a condom with her partner, of access to microbicides if they want children, or the guarantee of treatment access for a positive woman and her child?

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- o Where is the guarantee against negative judgmental attitudes from female health workers (many of whom are themselves struggling with violent relationships and HIV in their own lives)?
- o Where is the guarantee of that love, care and support from partner, family and friends, which makes adherence so much higher?
- o If all these criteria were very firmly in place, maybe then and *only* then might one begin to even *remotely* consider criminal proceedings but what about the effect of criminal proceedings not only on a woman's life but on her existing children? Let's not forget that all this ante-natal testing initiative has been driven from the outset by a well-intentioned, but ill-conceived and I use that word advisedly determination to create an "AIDS-free" generation. I would have thought that sticking a child's mother in prison and branding her as a criminal was a pretty sure-fire way of ensuring that this child is going to be more vulnerable than ever to not just having HIV but dying pretty fast of AIDS.

# AND WHAT ABOUT TESTING?

The spread of criminalization legislation means that many years of careful, committed and compassionate HIV prevention work in many countries are being blown apart overnight by people's fears that testing positive will mean that they could then be branded as disease vectors and as criminals. Men figure — quite sensibly — that if they remain ignorant of their status they can claim ignorance in a court of law. Women realize that they can avoid partner violence against themselves -and their children - if they don't have their status known or disclosed\*\*vi\*. This fear of knowing one's status, exacerbated by these consequences, is a disaster for prevention, especially since most HIV transmission takes place amongst those who are unaware of their status.

LET'S LOOK quickly at the crisis here in the UK also. The gulf even here, between the scientific facts and popular scare-mongering, based on deeply rooted prejudices, shock and amaze many of ICW's African colleagues. Just 10 days ago, I saw a report in the Daily Mail which was full of utter factual rubbish about HIV contagion<sup>xvii</sup>. The Daily Mail is mild compared with some. Some HIV-positive women in the UK are being told by their doctors that they shouldn't start new relationships, in case they might be criminally convictedxviii. Many in the UK also believe that women should never have sex – or children – if they are HIV positive. Parliament, the Home Office, judges, police, the media, health workers, teachers, social workers - and the public at large - we all urgently need to educate ourselves about what HIV is and what it isn't. And until we firmly address the mess, crisis and heart break we have for the thousands of positive women - and men - here in the UK, we can't legitimately criticize other states for what is happening within their jurisdictions. We all have an obligation to uphold the human rights of people with HIV. We all have an obligation to understand the critical fact that good treatment access means good prevention since transmission risk with an undetectable viral load is negligible. We all need to uphold the rights of all women - whatever their HIV status - to a life of peace, free from physical, sexual and psychological violence and to a life of sexual and reproductive choices.

### THERE ARE GLIMMERS OF HOPE OUT THERE.

a) The US political sea change is fundamental. US domestic and foreign policy have had a huge lot to answer for here: that original Model AIDS Law, for instance, was US-backed<sup>xix</sup>.

- b) Next that Swiss evidence which showed neglible transmission of HIV when someone has an undetectable viral load has just been used to overturn the imprisonment of an African man in Geneva, who had not even passed HIV on to anyone<sup>xx</sup>. This landmark courtcase is a huge victory for humanity and scientific fact over prejudice and racist scare-mongering and is being widely welcomed around the globe.
- c) Thirdly, women's rights groups are realizing also that these criminalisation laws are not gender-specific and indeed are tipped firmly against women in so many countries, including the UK. It just doesn't work to create a law in the hope that it will stop men from spreading HIV to women when in fact the people who are being forced to know their status first everywhere are women when they are pregnant. I am yet to meet or hear of one man who has purposefully gone out to spread HIV far and wide. Fear and denial you meet in plenty, but locking people up won't cure them of their emotions. Criminalisation just drives everybody and everything underground and is an inhumane way of treating practically anyone with a virus<sup>xxi</sup>.
- d) UNAIDS and various key NGOs are now working actively to raise global awareness of the pitfalls of these laws, and promoting more humane, more protective legislature to replace these damaging laws<sup>xxii</sup>.
- e) Last but not least, ICW calls on governments to engage comprehensively with HIV positive women ourselves who have critically been given the opportunity to be trained in understanding the pitfalls of these laws before considering any punitive legislation<sup>xxiii</sup>. We are also interested in exploring the potential for restorative justice, as used here in family law and mediation courts, and not adversarial law at all, to address these painful issues.

Here we all are, 60 years on from the UN Declaration on Human Rights. We must, between us all, keep up the pressure to roll out universal sex and relationships education, for young people especially, in order to support them to stay HIV negative; we must also recognize universal *treatment* as a *key part* of *prevention* and recognize with humility how one day HIV could affect each one of us personally. Just imagine having laws that instead of criminalizing *transmission*, were introduced and *used*, actively and consistently, to outlaw all inaccurate press reports, all discrimination against women – and men – with HIV, all police breaches of confidentiality, all ostracism of children with HIV in their families. These, together with positive active and consistent investment in education campaigns about what HIV really is – and what it isn't – would be far more effective. If women – and men – with HIV had been encouraged and supported to be involved from the outset in making policy decisions and rolling these out in practice, many of these crises would have been averted. We still live in hope that it's not too late and that the flames of this inferno called HIV can at last be contained.

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http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2009/20090105 Know your Epi.asp

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http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20081204\_Firstladies.asp

<sup>&</sup>lt;sup>i</sup> See <a href="http://publications.oxfam.org.uk/oxfam/display.asp?ISBN=9780855986032">http://publications.oxfam.org.uk/oxfam/display.asp?ISBN=9780855986032</a> for further discussion of this.

ii See www.sophiaforum.net for an audio file of Helena Kennedy's speech.

iii See <a href="http://www.icw.org/node/421">http://www.icw.org/node/421</a> for a full report on this.

iv See for instance p2 of <a href="http://www.pathfind.org/site/DocServer/Pathfinder.PMTCT4-lite.pdf?docID=4041">http://www.pathfind.org/site/DocServer/Pathfinder.PMTCT4-lite.pdf?docID=4041</a>; and also <a href="http://www.i-base.info/htb/v9/htb9-3-4/Very.html">http://www.i-base.info/htb/v9/htb9-3-4/Very.html</a>

v http://www.saez.ch/pdf f/2008/2008-05/2008-05-089.PDF

vi See http://www.icw.org/files/Access.pdf

vii See <a href="http://womenandaids.unaids.org/themes/docs/UNAIDS%20VAW%20Brief.pdf">http://womenandaids.unaids.org/themes/docs/UNAIDS%20VAW%20Brief.pdf</a>; and <a href="http://www.icw.org/files/Violence.pdf">http://www.icw.org/files/Violence.pdf</a>; and

viii http://www.aids2008.org/Pag/ppt/FRPLO102.ppt

xi http://www.unfpa.org/upload/lib pub file/523 filename abuja call-to-action.pdf

xii http://www.icw.org/files/ALQ%20Sept%202006%20-testing%20-.pdf

http://www.amnesty.org/en/library/info/AFR53/001/2008/en

xiv http://www.ajol.info/viewarticle.php?jid=46&id=44718&layout=abstract

xv http://www.icw.org/node/354

xvi In South Africa women are travelling up to 60 kms from their homes to seek ante-natal care away from their neighbourhoods, for fear that they will be tested for HIV before receiving care, that the HIV test will be positive, and that if this information was known in their communities that they would experience violence. Dr Johanna Kehler, AIDS Law Project, pers. comm.. Oct 2008.

xvii http://www.dailymail.co.uk/news/article-1152437/Foster-carers-told-babies-HIV-positive-protect-childs-human-rights.html

xviii See also http://www.poz-fem-uk.org/resources.html

xix See <a href="http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=907">http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=907</a> for a full summary of this. See too <a href="http://www.opendemocracy.net/blog/alice\_welbourn">http://www.opendemocracy.net/blog/alice\_welbourn</a> Hear also Justice Edwin Cameron at <a href="http://www.kaisernetwork.org/health">http://www.kaisernetwork.org/health</a> cast/hcast index.cfm?display=detail&hc=2941

xx http://www.nam.org.uk/en/news/CEFD90F2-34F1-4570-B9CF-1F0DB462AC9D.asp

xxi See http://www.ippf.org/en/What-we-do/AIDS+and+HIV/Verdict+on+a+virus.htm and http://www.soros.org/initiatives/health/focus/law/articles\_publications/publications/10reasons\_200809\_18?skin=printable

xxiii See <a href="http://data.unaids.org/pub/Manual/2008/20081110">http://data.unaids.org/pub/Manual/2008/20081110</a> jc1601 polbr criminalization long en.pdf xxiii See articles at <a href="http://www.icw.org/node/354">http://www.icw.org/node/354</a>