

## SLIDESHOW TALK DCN/UNIFEM ON-LINE WORKSHOP on HIV CAUSING GBV.

November 2010. Alice Welbourn Salamander Trust.

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### 1) INTRODUCTION

Hello and welcome to the final set of slides in this series. I am Alice Welbourn, Director of the Salamander Trust and I apologise for my croaky voice. I am recovering from flu. You have already heard from Fiona Hale about the definitions of violence against women and some of the statistics about experiences of violence by women living with HIV; and from Marijo Vazquez about existing projects and programmes which show some signs of success in tackling these issues. In this presentation we are going to look at some of the strategic issues for advocacy, research, programming and policy.

### 2) STRATEGIC ISSUES

So to begin with some strategic issues. Here we draw out three which we think are key.

The first is that whilst there is a huge amount of information, awareness and growing data about violence against women *causing* HIV, there is still little awareness about the amount of violence against women *caused* by an HIV diagnosis. This is what this whole seminar is seeking to address.

Secondly, we consider that narrow understandings of what constitutes “evidence” mean that violence against women with HIV is still not taken seriously, because there is little “evidence” – ie little formal scientific research has to date been conducted – to “prove” that it is an issue. However, as Shirin Heidari, Editor of the Journal of the International AIDS Society, recently stated, “absence of evidence does not mean evidence of absence”. So we really need to be thinking much more clearly here about our attitudes to an evidence base or a lack of one, when things are happening to women that are making them feel especially vulnerable, lonely and isolated. We also need to be aware, we think, of the on-going domination of medical models of care, which frame scientific enquiry. For instance the WHO Global Burden of Disease makes no reference at all to violence as an outcome of HIV. Most of its disease definitions are based on physical disease manifestations – yet as any woman who has experienced any form of violence will attest, whilst bruises might fade away there are many other long-lasting consequences of experiencing violence which never fade from memory.

HIV positive women’s efforts have certainly increased awareness of the violence issues. Indeed, when we positive women come together to talk about our experiences of violence, the palpable relief of many to learn that they are not alone, that this is happening not just to *them* – and not just *because* of them - but to thousands of *other* women around the world, is very moving. So we need to be thinking about and asking ourselves constantly about what *other* issues like this are also out there that positive and other marginalised women are experiencing

in loneliness, fear and isolation, which often means that the issues are invisible and remain unvoiced – unless researchers reach out to positive women to *ask* us and *learn* from us.....

### **3) ADVOCACY**

So moving on then to key advocacy issues.

We are glad to see that UNAIDS recommends that “all forms of violence against women and girls are recognised as violations of human rights and are addressed in the context of HIV. We are also glad that UNAIDS also recommends that HIV should be included in the Secretary General’s UNiTE to end violence against women campaign. Ideally we would like to see *all* the UN agencies assess their policies, guidelines and practices, in order to ensure that all forms of violence against women and girls living with HIV are avoided.

We see that there are 3 key approaches to this work:

- i) bottom-up and community-based approaches, some of which Marijo highlighted in her presentation;
- ii) Strengthening the ability of health professionals to recognise and address violence against women living with HIV in their care;
- iii) And perhaps most importantly, since health workers wield such power and can command such huge respect or fear in local communities: we need to be creating institutional cultures of respect and care for people with HIV – and cross-referral with other disciplines. This is in light of the recognition that neither HIV nor violence are “just” health issues – but that these and gender

issues are governed by and also influence so many different aspects of our lives. If these principles of a human rights approach in attitudes and practices of service providers; and a culture of cross-referral between disciplines were to be institutionalised, then we could really start to understand much more and achieve much more in supporting positive women experiencing violence in all its forms.

This leads on to our third paragraph here, which is that violence is often not recognised for what it is. We need to start *labelling* stigma and discrimination as violence, we need to start recognising that mandatory testing is violence, we need to start recognising that testing *any* woman during pregnancy for a chronic condition, from which she is likely to believe she is going to die, and because of which she is going to be treated badly by those who have tested her, is violence. We wouldn't advocate testing women for *cancer* when they are pregnant. Yet, because of the risk to a woman's *child*, it is considered acceptable to put aside a woman's rights and feelings for the *sake* of her *child*. Yet when we look at this more closely, there are huge human rights issues here – for the child as well as for the woman. Musimbi Kanyoro said “every child deserves a mother.” Who else is best placed to keep that child happy, healthy and well in the world? Moreover, research by Karr-Morse and Wiley (1997) and many others has shown that children whose mothers have experienced extreme stress during their pregnancy have themselves suffered as a consequence after they are born. Why is it that when it comes to women and HIV, the research already well grounded in other disciplines seems to vanish like dew in the desert? We *have* to institutionalise a firm recognition that we need to be looking at a clear and close

linkage between the Convention on the Rights of the Child and CEDAW throughout our work on HIV and vertical transmission. This isn't an either/or – it's a both/and situation. This thinking is critical to our finding an effective and humane way forward – for both women *and* their children. We should be moving towards a human rights based framework where all testing of women – and men – can take place as part of a voluntary, confidential *pre*-conception process, aligned with good comprehensive sexuality education for girls and boys alike and good sexual health services for all. This would be best for women – and best for their children, if and when they choose to have them.

#### **4) RESEARCH**

Moving on then to a research agenda.

UNFPA has identified that there is a current 'lack of reliable and comparable data on violence against women and girls – and even less on violence against HIV+ women. Whilst there are far more data emerging on the former now, thanks to the work of researchers at the LSHTM and WHO and others, there is still not yet good research on *why* violence against women occurs at all, or on links between social determinants, risk factors and so on; So this is clearly an area which needs further exploration.

Next we need to be thinking about different approaches to building the evidence base. Again, if we look to other disciplines we have valuable models. The work of Robert Chambers and others in the agriculture and general development world already in the 1990s around *who* is asking the research questions, *framing* the

research agenda – Whose *knowledge* counts and Whose *Reality* Counts – are classic texts from which we can learn much in terms of participatory forms of learning, enquiry and sharing.

We also need to develop more effective ways of conducting research which move away entirely from the extractive medical models, so that community members themselves – in this case women with HIV themselves – can become a core part of the learning, analytical and action team. This is nothing other than good practice and already has precedents in the medical community. For instance the work of Michael Alpers and colleagues in Papua New Guinea to tackle and eradicate kuru there has been based wholly on 50 years of collaborative research with community members

(<http://www.med.monash.edu.au/news/2009/michael-alpers-biography.html>).

Ann Macaulay and colleagues in Canada have spent many years working with First Nation communities on participatory diabetes research to great acclaim

([http://www.cfpc.ca/local/files/Research/Section\\_of\\_Research/FMF%202008%20Awards%20FM%20Res%20of%20the%20Year\\_doctor.pdf](http://www.cfpc.ca/local/files/Research/Section_of_Research/FMF%202008%20Awards%20FM%20Res%20of%20the%20Year_doctor.pdf)). Similarly, Dr

Rupert Whitaker of the Tuke Institute has spelt out the critical role that community members can play in research, planning, implementation and evaluation of programmes.

Next, we need to hold leading agencies to account in what they do and don't say – and how they say them – in their reports. Here is one recent example from WHO's HIV department which is fairly breath-taking. This bald statement makes no reference whatever to the reason *why* more women are accessing ARVs than

men – ie because they are being targeted in ANCs. Nor is any reference made to the challenges faced by positive women in *taking* these ARVs – you will remember the woman in one of Fiona’s stories in this respect, whose violent husband locked her out of the house, so she couldn’t take them. When I enquired recently of UN officials why we couldn’t do sentinel site testing and reporting on HIV prevalence amongst male police and army staff, as well as among pregnant women, I learnt what should have been obvious to me – that these staff *are* tested also – but that the results are not published because they are considered to be state secrets. Well that tells us also a great deal, I think about the status of positive pregnant women in our communities.

## **5) RESEARCH contd.**

Moving on, we highlight here a few sidelined issues which we consider warrant more research.

Little is known, for instance about women’s experiences of loss or *fear* of loss of their children upon an HIV diagnosis, or when the sick husband whom they have cared for has died. We certainly know that many women stay in abusive relationships for fear of what will happen to their children if they leave. We also know that many HIV positive women are caring for their own and relatives’ children with HIV. So this is clearly an area that needs good research.

We also need to look at another huge area – of food, water and fuel security and sovereignty. Research I conducted for the Liverpool School of Tropical Medicine in 1990 on the socio-economic dimensions of poverty and ill health in West

Africa showed clearly that there are strong links between seasonality, food insecurity, poverty, disease, quarrelling and domestic violence – but this was before the added dimension of HIV was thrown into the pot. Given the huge importance of food security and basic nutritional quantity, let alone quality, in many communities in high prevalence countries, before even ARVs can be considered, this is an area that warrants far more attention than has yet been paid to it.

Linked to this also – in E Uganda in 1996, further research showed how older women reported that they were facing famine in their homes because they were looking after sick husbands and grandchildren and their crops were being choked by weeds in their fields. Some of these women were themselves HIV positive also – but this is a clear example of how HIV deeply affects not just individual women living with the virus, but also those closely involved with their care or care for their relatives. These older women were both physically and mentally exhausted by the strain of sickness, death, grief and fear for their own and their grandchildren's futures. This too is a form of violence, since others in the community, whilst they knew what was causing the illness and deaths, had not previously reached out to support these women or learn about their food insecurity. So further research is needed here also.

Small wonder then that we also recommend urgently research to be conducted on links between HIV and violence, mental health and chronic depression issues for women. Classic signs of chronic depression include many symptoms which are very familiar to positive women – self-blame, hopelessness, lack of self-

worth, feelings of guilt, fatigue, insomnia. Yet all too often this gets labelled as “self-stigma”, as if positive women only have themselves to blame for this, rather than recognising that positive women are actually clinically depressed, often as a consequence of post-traumatic stress as a result of their diagnosis – and often also as a result of how they have been treated *since* the diagnosis.

Last but not least, we call for research on the impact of development interventions on positive women – especially in relation to supposedly simple techno-fixes like cash transfers or medical male circumcision. Simple solutions are always highly attractive on paper or in controlled trials and rarely effective when rolled out in the real world, without a lot of community involvement and collaboration. Research from the WHiPT project led by AVAC and ATHENA and partners makes it clear the positive women are experiencing gender violence from partners who have been circumcised who now believe that they are wearing a permanent condom. The work of Susan Johnson and others makes it clear that micro-credit schemes, which include cash transfer schemes, are notoriously challenging without in-depth research amongst and collaboration with expected beneficiaries.

## **6) PROGRAMMING AND POLICY DEVELOPMENT**

Moving on them to programming and policy development:

We recommend that a lens of recognition of the widespread existence of violence perpetrated against women living with HIV be used to analyse policies and programmes across all UN bodies, government departments, NGOs of all kinds,

faith groups, service providers and other sectors of society. Women who themselves are affected by these issues are inevitably well-suited to be involved in such analyses.

In the spirit of GIPA also, we also recommend that all policies and programmes must be based on the “meaningful involvement of women living with HIV and AIDS”. This isn’t just a nice idea, it’s about making initiatives effective. Many of you will have seen the ICW participation tree, based on Roger Harts’ ladder of participation designed for UNICEF in the 1980s. It is ironic that even though this ladder of participation for children is so enshrined in good practice in terms of working with children, their *mothers* and *other* women in general, let alone *positive* women, have such a long way to go yet to achieve this. Yet again, quite apart from positive women’s own rights in all this, surely, the best thing for a child is to have his or her own mother, grandmother and aunts healthy, happy and well. How come we think about children in isolation from all the adults in their lives?

Next, violence against women living with HIV requires a multi-sectoral approach. For instance there are many different loci of violence and forms of violence for positive women, many of which may have nothing to do with having children or with health service provision. We need to adopt this multi-sectoral approach in reflection of that “social determinants of health” diagram that we began with, reflecting that this could also be a “social determinants of violence” diagram. An example of how this might work in practice is explained in a document we

prepared in 2004 for UNHCR for the Asia-Pacific Region, entitled “Oh This One is Infected” which appears on the reading list.

Finally, we need to remember that we are all in this for the long haul. There are no quick techno-fixes, there are no simple solutions. It took 60 years for European governments to ban smoking in public places, even though it has been that long since the medical evidence of the dangers of smoking emerged. This calls for long term *financial* investment in programmes with men and women, girls and boys alike, to address the deeply entrenched attitudes and practices in all our societies globally. Things *can* change – we’ve seen it happen. But we can’t just rush in with laws and declarations and insistence that things *must* change or we risk having to hold ourselves to account for further violence towards the very women we seek to protect.

## **7) CONCLUSIONS**

In conclusion therefore, we come back to four key issues.

Violence against women living with HIV is about power and its abuses. Power is not something finite, something that if “I” have, then “you” don’t have. We consider “power” to be something which is *infinite*, which can and should be shared and which leaves all those who share it benefitting together from more than the sum of its parts.

We have been addressing all that we have written and discussed in a framework of believing that gender equality is a human rights issue.

We believe that a non-violent approach is the way forward in this work – just as Albert Einstein said – “We cannot solve our problems with the same thinking we used when we created them”. So we need to ensure that we engage with this issue using non-violent forms of communication, negotiation, understanding and collaboration, in order to move forward into new ways of experiencing, thinking about and acting in the world.

We don't think it's any surprise that peace lies at the heart of the doctrines of all the great world faith systems – Christianity, Judaism, Islam, Hinduism and Buddhism alike.

We also know from the work of philosophers such as Lakoff and Johnson, of psychologists like Seligman, and of psychiatrists and neuroscientists such as Schore and Siegel that we are the embodiment of the language that we use in the world, and that we can create our futures by the words and mindsets that we adopt. In order to *practise* peace, we need to *think* peace – and this begins with us.

## **8) SOME REFERENCES**

So that's it from Fiona, Marijo and myself. Here are some references for you and we can send the others through also. We wish you all a very successful final seminar week. Many thanks for listening. Goodbye.

- 1) Shirin Heidari quote – [Open Democracy](#)
- 2) More than a pound of flesh – [Open Democracy](#)
- 3) Global Burden of Disease - [WHO](#)
- 4) Getting health care professionals to recognize violence against women in their care.... [HIV, Women and Motherhood project](#)
- 5) Musimbi Kanyoro ref – [IWS Nairobi 2007](#)
- 6) Karr-Morse and Wiley (1997) [Ghosts from the Nursery](#)
- 7) CRC [reference](#)
- 8) Human rights framework – [Gruskin and Ferguson](#), [Tarantola](#)
- 9) CSE – [UNESCO](#)
- 10) SRHR/HIV [Cochrane Review](#)
- 11) [Robert Chambers](#) – Whose Knowledge Counts: Whose Reality Counts
- 12) Michael Alpers - (<http://www.med.monash.edu.au/news/2009/michael-alpers-biography.html>).
- 13) Ann Macauley - ([http://www.cfpc.ca/local/files/Research/Section\\_of\\_Research/FMF%202008%20Awards%20FM%20Res%20of%20the%20Year\\_doctor.pdf](http://www.cfpc.ca/local/files/Research/Section_of_Research/FMF%202008%20Awards%20FM%20Res%20of%20the%20Year_doctor.pdf)).
- 14) Similarly, Dr Rupert Whitaker of the [Tuke Institute](#) has spelt out the critical role that community members can play in research, planning, implementation and evaluation of programmes.
- 15) Child Custody [Issues](#)
- 16) [Food security issues](#) – Liverpool School; TASO Uganda
- 17) “Making [lemonade](#) out of lemons”; WHO docs;
- 18) Cash transfers – [Banthia](#) et al ILO article
- 19) Medical male circumcision – WhiPT – see [ATHENA](#) after 1 Dec 2010
- 20) ICW [Participation](#) Tree
- 21) Hart’s [Ladder](#) of Participation
- 22) [“Oh this one is infected”](#)
- 23) [Smoking ban 60 years later](#)
- 24) [Lakoff and Johnson](#)
- 25) Martin [Seligmann](#)
- 26) Allan [Schore](#)
- 27) Daniel [Siegel](#)