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Gender, participation, health and positive thinking: a personal perspective

by ALICE WELBOURN

Introduction

This year, I have personally witnessed the following three incidents:

- A senior World Bank staff member, based in Washington, stated that it is not possible for the World Bank to liaise with HIV positive women's networks in different countries, because the latter didn't have the capacity to consult with the Bank properly.
- A senior Geneva-based World Health Organization (WHO) staff member 'reminded' me that when WHO is hosting a meeting with 'partners', it is WHO's prerogative to set the meeting date without any outside consultation.
- Another senior Geneva-based WHO staff member, stated that it is WHO's policy to ensure that all HIV positive women will have access to anti-retroviral therapy by making them available through ante-natal clinics.

I find these three statements very disheartening since they are made by people who are in power, by people who are relatively highly paid and highly trained, and who are meant to be experts in their fields.

This article is a personal account of some of my experiences of approaches to sexual and reproductive health that promote gender, generation, representation and participation over the past 15 years or so. Although it is a highly personalised account, I hope that it will echo the experiences of many of those reading it.

Waking up to reality

Sexual and reproductive health has come a long way in the last 15 years in relation to the international development scene (see Gordon and Cornwall, this issue). Twenty years ago, it wasn't on the agenda of any major international development agencies, other than through support for maternal and child health (MCH) clinics and through traditional birth attendant (TBA) training, which both focused on women's roles as birth-givers and child carers. Both are important roles for a woman, but far from being her only tasks or roles in life. In those days, agencies considered that anything to do with sex, relationships, gender, commercial sex work, or drug use was way off-limits and had nothing whatsoever to do with 'development'.

How the world has changed. A Panos report, written in 1991, stated that:

...with the WHO projecting a cumulative total of 4 million adult AIDS cases worldwide by the mid-1990s, the epidemic is beginning to affect the economies of a number of countries.

Indeed, by December 2002, UNAIDS reported that the total number of people with HIV/AIDS in the world was 42 million (of whom over 50% are women). Newly infected people alone in the year 2002 numbered 5 million and 3.1 million people died in 2002 alone. (UNAIDS, 2002).

With these figures now a reality rather than 'just' a projection, the 'international development' world has been forced to wake up to the harsh truth that many countries'

ICW staff and trustees held a workshop to review their International Strategic Plan 2003-2007 to measure progress against its objectives and to identify new areas that need more work



Photo: ICW

gains of recent decades, in terms of life expectancy rates and gross national income, have fallen back to levels previously recorded in the sixties.

HIV and AIDS has cut swathes through Africa's people of reproductive age especially, and is set to do the same soon in Asia, Latin America and Eastern Europe.

The increasing impact of HIV and AIDS

In reading others' contributions to this 50th edition, I was struck hugely by the continued similarity of the issues that face us all in this 'participation' movement, no matter what issues we address. For instance, you could substitute 'HIV positive people's rights issues' for 'children's rights issues' in many aspects of Chawla and Johnston's chapter (section 7); Archer and Goreth's summary of principles of literacy education (section 4) and Pimbert's Table 1 on institutionalising participation and people-centred approaches (section 14), speak equally to issues facing workers and activists in the sexual and reproductive rights movement. The discourse on globalisation and participatory resource management in Pimbert's article (Box 3) echoes closely the challenges facing those of us campaigning for global access to anti-retroviral (ARV) drugs, given the stances of the Bush Administration, the transnational pharmaceutical companies, and other key global financiers.

It also struck me that the other contributors have hardly mentioned HIV in their articles. Perhaps they feel that this is because it will be 'covered' by this one. However, all the hard work in their own fields will come to nothing if the people they have worked with around the world have died. Instead of repeating their clearly articulated reflections, I offer here therefore a more personalised viewpoint.

Here are some extracts from the UNAIDS epi-update 2002 report:

The epidemic is also sapping the government's capacity to support small-scale farmers. Despite increasing mortality among extension workers, the training and recruitment of replacement workers all but halted in 1995.

According to the United Nations Food and Agricultural Organization (FAO), seven million agricultural workers in 25 severely affected African countries have died from AIDS since 1985. It warns that 16 million more could die in the next 20 years if massive and effective programmes are not mounted.

As the impact of the epidemic grows more severe, it strips households and communities of valuable labour power. Adults become ill and less able to attend to agricultural and other work, including wage labour. Some 60% of commercial and smallholder farmers in Namibia told researchers in 2001 that they had suffered labour losses due to HIV/AIDS. Others—typically women and children—are also drafted in to care for the ill, thereby reducing the time and energy they can devote to paid labour or farming tasks. In badly affected areas, regular funeral duties can have similar effects.

The agricultural output of family-based farmers and their supplementary incomes from wage and other paid labour—so vital to food security in many low- and middle-income countries—cannot be sustained in such circumstances. Fields are more likely to be left fallow and smaller areas kept under cultivation, weeding is neglected, infrastructure (such as fences and irrigation ditches) falls into disrepair, and pest-control becomes too expensive.

Almost 1 million people in Asia and the Pacific acquired HIV in 2002, bringing to an estimated 7.2 million the number of people now living with the virus—a 10% increase since 2001. A further 490,000 people are estimated to have died of AIDS in the past year. About 2.1 million young people (aged 15–24) are living with HIV. The early death of farming parents disrupts the transfer of knowledge and skills from generation to generation. Children growing up as orphans have fewer opportunities to learn how to use and sustain land and to prepare nutritious food for family members. The widespread loss of this intangible, but essential, good could have severe and long-lasting consequences for food security in the region. At the moment, very few steps are being taken to counter this growing reality.

Two participants of the Young Women's Dialogue held in South Africa, this year. The dialogue brought together young African women living with HIV and AIDS in a safe space for young women to share experiences about the challenges of HIV/AIDS and to develop advocacy campaigns for highlighting the gender and human rights-based challenges faced by participants in each of their countries



Photo: ICW

In 1992, I myself learnt the hard way about the impact that HIV can have on ordinary people's lives by discovering that I too, am HIV positive. Despite all my years of good education, good health and close network of friends, my access to information about routes of HIV transmission and my concern to inform others with whom I worked, I too had acquired this virus. It's taken me 11 years to 'go public' with this information, fearing what the neighbours might say, wanting to protect my children from taunts at school, fearing in the early days that I would be dead within months. Luckily I am still here, thanks to the advent of ARVs, and, thanks to the wonderful support of my family, friends and close colleagues.

So, as a way of trying to make sense of what had happened to me, in the same way that many activists are born, I decided to start to work specifically on gender, HIV and AIDS, to try to alert others to the enormity and complexity of the issues involved, in order to try to make life less dreadful for others who received this diagnosis and to try to help others *not* to get infected in the first place. This was my fundamental coping strategy, as much to do with helping to keep myself sane and alive, as it was to do with helping anyone else. When organisations and individuals

work with and support HIV positive people around them, in truly respectful, equitable and meaningful ways, they are doing much to help to keep us alive, active and well, as well as learning from our many personal insights of living with this virus.

Luckily I am fit and well and have responded well to the ARV drugs. Although many friends have had unpleasant side effects, the drugs have made a huge difference, actually keeping us alive for a start and easing the relentless stress of the many funerals that many of us went to in the earlier 1990s. I exercise regularly and lead a normal life. I work a nine-hour day and I look just like the next person. No one would guess that I have this virus in my body and that I have had it for over 14 years.

Tackling the issues

The issues which I, as an HIV-positive activist, and my colleagues are having to tackle on a daily basis, are the issues highlighted in the opening quotes of this article. These issues are summarised below.

Learning how to learn from others

Many international financiers and policy-makers consider

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that others have to learn to engage on **their** terms, rather than recognising any need for themselves to learn how to learn from others in more open, interactive, participatory ways. The work that the International Planned Parenthood Federation (IPPF) and others have done to ensure that young people are now represented on all its regional boards – and that the methods used for the meetings of those boards are interactive, participatory and **fun** – have much to teach us all about how barriers of communication and representation between ‘us’ and ‘them’ can be broken down effectively and how the skills and insights of those who previously had no voice **can** be heard effectively. (Faulkner and Nott, 2002)

Working in partnership

Many in the UN, donor agencies, governments, NGOs and other institutions believe that ‘partnership’ means that those who hold the purse-strings control the agenda, the invitation list, and the time and the place for their meetings. Many of the articles in *Participatory Learning and Action* over the years have highlighted how critical it is to develop codes of courtesy, respect and equity with those with whom we seek to work. It would be good for such articles to become required UN reading.

Changing attitudes towards women

We need to challenge attitudes that stereotype women as reproducers, which are reflected in the views of WHO and other institutions, which assume that if HIV drugs are made available at ante-natal clinics, then enough women will receive access to treatment without them having to think much further about us. What about girls below the locally accepted reproductive stage, what about women who are barren or who may wish to have a break from having children, or those who wish to have no children – or women who are past child-bearing age? All of us may need HIV treat-

ment too – yet at present there is *no* provision within the WHO 3x5 strategy for any of us¹.

Sharing the platform

There is a need to challenge the views of similar bodies – as well as the views of many activists – especially men – around the way in which men and male institutions lead the world, without even any awareness of their exclusion of others from meaningful engagement and debate. This is, perhaps, the hardest nut to crack. One man recently told me, ‘Oh well, you women just need to stand up and speak out’, yet he would not accept that he too had a responsibility to ensure that he was sharing the platform from which he spoke with **women** as well as men.

These are all views with which we find ourselves taking issue on a daily basis and which cause us huge stress. Other issues, which we also regularly witness, also need addressing.

Thinking beyond the individual

The dominance of Western ways of thinking, promoted by Descartes, in his words: ‘I think, therefore I am’, assumes that the individual is central to their world. This thinking is also central to the belief that HIV happens only to ‘people out there’ and isn’t something which affects **all** of humanity. Descartes’ thinking has been clearly and comprehensively challenged and thrown out by Satish Kumar, in his excellent book ‘You are, therefore I am: a declaration of dependence’ (Kumar, 2002). Even Satish Kumar, alas, overlooks issues of gender inequality in this analysis – but his works should be required textbook reading for all those who aspire to work in international development.

Listen to the evidence

There is a dominance of Western lines of thought amongst donors, which promote the need for theory first, before practice, rather than realising that these two are constantly intertwined in a give-and-take relationship. Thus many donors dismiss as ‘anecdotal’ repeated stories from many HIV positive women in many different parts of the world, which relate the same tales of human rights violations (such as lack of confidentiality, forced abortions and sterilisations, being thrown out of their homes, or off their land, being separated from their children, and so on) at the hands of their health workers, their in-laws, their communities and policy makers. Since these women are often sick, penniless, ostracised by

¹ The WHO ‘3x5 strategy’ is to ensure access to anti-retroviral therapy for three million people by the end of 2005. This is estimated to be half the number of HIV positive people who will actually need it by then. While most welcome in principle, it demonstrates no awareness of issues of access relating to gender.

The Voces Positivas project in Central America and the Caribbean. HIV positive women from 12 countries in the region participated in an innovative and inspiring process of empowerment and training which they are now replicating in their home countries



Photo: ICW

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their neighbours, they have to have iron wills to organise themselves, set up self-help support groups, share their stories, and start to document them, speak out for their rights and make calls to policy makers to change local practices to support those rights. Many thousands of such groups exist around the world – yet the world still dismisses their calls, because they haven't yet been 'properly' documented by 'official' researchers and aren't based on 'evidence'. And yet we find it highly difficult to find any donors who are prepared to fund multi-country studies on **our** terms, which will enable such groups to consolidate their experiences and recommendations. Where is the justice in that?

Who owns the knowledge?

Time and again we see the violation of intellectual property rights. Just as with the plans of Western scientists to patent indigenous seed species and even human DNA, there is widespread plagiarism practised by some NGOs, especially some international NGOs. Although there is much good work created and carried out by many NGOs, others adopt – and call their own – ideas and projects that are often based

on and created out of these self-help groups' lived experiences.

This practice is becoming increasingly widespread and should give us grave cause for concern. Recent examples include a practical, hands-on nutritional guide for HIV positive people, written by Lynde Francis, Director of the Centre in Harare, which provides nutritional advice, counselling and complementary therapy for HIV positive people in Zimbabwe. Herself HIV positive, Lynde has developed the Centre with colleagues out of their own collective experiences and this book builds on that rich personal experience. Recently, an international NGO has told others that **they** have produced the book, as if it is their own work. At the Barcelona AIDS Conference in 2002, a West African activist asked me: 'What is it with (Organisation X)? The new director used to be great, but if anyone joins that organisation, they start to act as if they invented everything: they steal our ideas and call them their own'. International NGOs can do this because those whose ideas they have stolen have little recourse to expensive lawyers – nor do they actually **want** anything more than fair and just acknowledgement for the

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huge amount of personal insights, energy and passion which they have put into these ideas. Yet many international NGO staff have not often had those personal insights themselves and use others' ideas to promote their own organisations, with little regard for the rights of those whom they call their partners.

Thankfully, the *Participatory Learning and Action* series editors from the outset have made it clear that articles should, wherever possible, be multi-authored, in order to respect the diverse wealth of experience which has created a new idea, rather than leaving authorship – and thus ownership – of new ideas in the hands of the elite.

Evaluating effectiveness

Another major cause for concern which is just emerging relates to the roll out of access to treatment, which is currently being planned by WHO (the '3x5' strategy). There is a **huge** need for monitoring and evaluation of this process, at grass-roots community level as well as at country-wide level, and it is imperative that this monitoring should be conducted in a truly participatory and disaggregated way, in order to ensure that there is equitable access for women and girls as well as for men and boys. Practitioners such as those of you reading this article could offer your services to HIV positive networks in your own countries, to work together **with** them to monitor this access and ensure that it is equitable.

Ethical frameworks

Just as crucial is guaranteeing the ethical involvement of HIV positive people in research. Much research carried out on HIV positive people, especially women, is extractive, disempowering, elitist, and ignores gender or generational issues. In response to these problems, the International Community of Women with AIDS/HIV (ICW), the activist network with which I am involved, has produced guidelines for ethical research that seek to promote more equitable processes (see www.icw.org).

Recommendations for good practice

You *Participatory Learning and Action* readers could make a huge difference to this pandemic. No doubt many of you are possibly HIV positive or have close friends or family who are, and are therefore yourselves only too aware of the issues raised here. For those of you not yet directly working on or touched by these issues, in addition to the observations above, I offer some further suggestions for action:

- Familiarise yourself with routes of HIV infection and consider the implications for you and your family and friends. HIV isn't about innocence or guilt: **no one** deserves to have HIV. It is a viral infection and until we remove the morality debate from the issue, and recognise that it is poverty, global power imbalances, and gender issues which fuel and fan the pandemic, HIV will continue to thrive and people with HIV will continue to die. (See, for example, Cornwall and Welbourn (eds) *Realizing Rights*).
- Promote solidarity with and support for HIV positive people around you: train, retain and employ HIV positive people, including women, at all levels of your organisation. An excellent document, 'Working positively' describes how you can do this together with local HIV positive peoples' networks (see 'Working Positively', UK Consortium, 2003).
- Promote solidarity with and support for HIV positive people in your own community. Talk with your neighbours about practical as well as strategic ways in which people with HIV and their carers amongst you can be supported by you all. Create enabling environments where positive people can feel safe to be open about their status with their own neighbours. (See the IDS Bridge Cutting Edge Pack, and ICW publications, for examples of good projects).
- Join forces with networks of positive people in your country to lobby for free and equitable access to anti-retroviral drugs for **everyone** with HIV; for food in their stomachs and also for drugs to combat 'opportunistic' infections. Generic drugs now cost as little as US\$140 a year, but global power politics is hampering their production and distribution. Ensure that these drugs are available not just for those who can afford to pay for them in towns, but also distributed by trained lay people, if necessary, in rural areas.

Only once people know that drugs are available and that their friends won't reject them will many dare to risk being tested.
- Explore and challenge the laws or practices in your own community, which deny women the right to choose to stay in their homes or on their land, or to keep their chil-

dren once their husband has died. If families spilt up once the husband has gone, poverty will drive the widow and her children towards further vulnerability to infection, and all chances of children inheriting generations of knowledge and skills from their parents will be gone.

- Ensure that girls, as well as boys in your community continue with their education. Many girls are taken out of school to help their mothers tend for the sick. Consider flexible timetables, to enable their schooling to continue. Make sure that both children and adults around you all read or have read to them 'Choices' by Gill Gordon.

- Write to heads of western governments to challenge their international recruitment policies, which leave other parts of the world empty of teachers and medical staff, without considering the consequences.
- Form a group with others in your own community, including religious leaders, politicians, health workers, teachers, CBOs, youth workers – and groups of HIV positive men and women – to question and challenge the social, economic, political and moral injustices, which have caused the pandemic to flourish in **your** community. Together, we **can** all make a difference.

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