11

Participatory approaches to HIV/AIDS programmes Semi-special issue

Alice Welbourn

· Introduction

Welcome to this semi-special issue on participatory approaches to HIV/AIDS. We welcome not only our regular readers, mainly practitioners of general participatory development, but also those who are directly involved in HIV and AIDS prevention, care and support work. We hope that this issue will help all development workers to increase their awareness of the influence of sexual health in general, and HIV in particular, on their work. Similarly, we hope that this issue will show HIV workers how participatory approaches can help them learn about the specific contexts of the communities with whom they work. In particular, this issue shows how the use of PRA can help people to feel empowered to address the issues around HIV for themselves. This empowerment, perhaps beyond all else, is our main weapon in the fight against the combined forces of fear and discrimination which feed the spread of AIDS.

This introduction will look first at some personal and professional aspects of HIV for development workers. This will be followed by a brief overview of the papers presented in this issue. I then conclude by returning to the mutual benefits of HIV work and participatory learning approaches.

Fear and stigma as a bar to learning

We need to acknowledge our own individual responsibility for prevention of HIV and care of those with HIV. People are often unaware that they are infected with HIV for several months, or even years, until symptoms begin to appear. Even when symptoms begin to appear, they may not be immediately recognisable as HIV. People with HIV can continue to lead normal, healthy, productive lives for several years after becoming infected. Therefore, most people do not realise that they may be infecting others (through, for instance, sex without a condom or donating blood) until a long time after the event. HIV is no respecter of different groups of people. Yet those with HIV are often greatly stigmatised and thus fear to speak openly about it. In this way, the opportunity to learn from them of their own experiences is lost. The best door to learning, through peer education, stays firmly closed. What can we as development workers do about this?

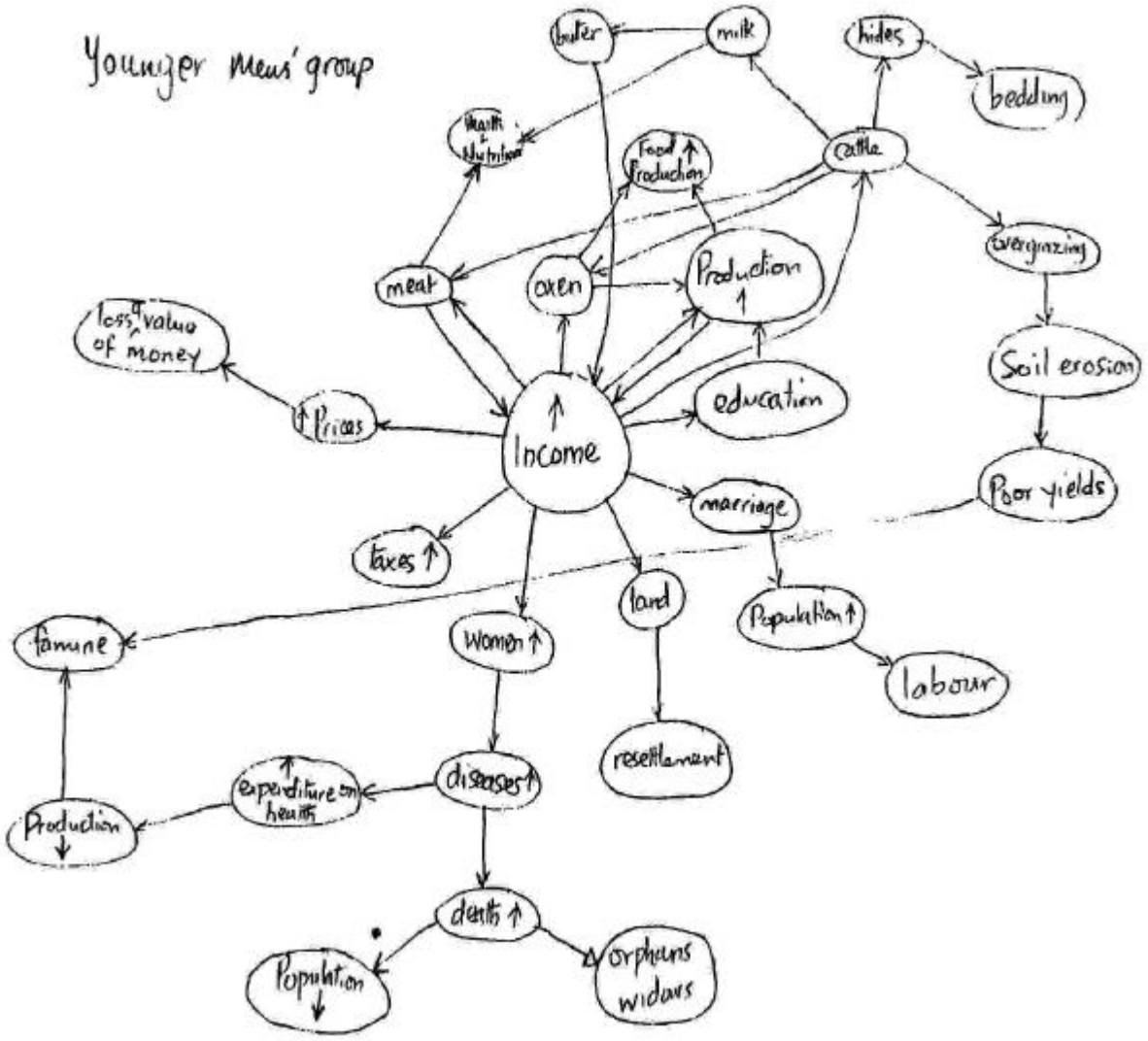
A personal level: AIDS affects all of us

As development workers we have often set ourselves apart from those with whom we work. Slowly, through the adoption of PRA and other participatory approaches, we have appreciated that community members are not different from us after all, in terms of intelligence and knowledge. The major differences between development worker and community member lie, not in these matters, but in access to opportunity, to education and to cash. Through PRA we have learnt that our role should not be to lecture at community members, but rather to empower them to develop their own solutions to the problems they face. This approach recognises that we have little to offer in the way of answers. Instead our potential strength lies in the role of facilitating a learning process in which the main actors and decision-makers are community members themselves, and in which we too as development workers have much to learn.

Source: PLA Notes (1995), Issue 23, pp.57–61, IIED London

As we see the increasing social, economic and psychological pressure which HIV and AIDS is having on individuals and communities around the world, it is our responsibility as development workers to turn our new-found learning to address AIDS. Much early HIV work focused on a top-down, ABC approach to the problem: *"**A**bstain, **B**e faithful or use **C**ondoms"*. Predictably, this approach had little effect. Thus HIV workers have started to use approaches such as PRA which begin with what community members themselves understand about the issues.

Figure 1. Flow diagram showing effects of increased income



Source: PLA Notes (1995), Issue 23, pp.57–61, IIED London

A professional level: how AIDS is a development issue

As development workers we need to recognise that our development interventions may inadvertently increase rates of HIV transmission amongst target communities. We have a responsibility to help communities to recognise this possible outcome and to define ways for themselves of limiting the possibility.

Figure 1 illustrates the kind of problem which faces many of us. It was produced by a group of young men in Seroti in Eastern Uganda, during a PRA training workshop[1]. Seroti is a drought-prone area where livestock are of great economic importance. The young men had been asked to comment on the likely effects for them of increased income, brought about by a planned re-stocking programme in the area. Such programmes, if well planned and managed, are generally considered to be valuable ways of helping livestock owners to get going again after a period of drought.

The men quickly made wide-ranging links to many different aspects of their lives, including labour, population, soil erosion, taxes, food production and so on. Of particular interest here is the direct link which they made with women. They expected the number of sexual liaisons they would have with women to increase, and described how this would lead to an increase in sexually transmitted diseases, including HIV. They foresaw that this would result in increased health costs, death, orphans, widows and famine, and reductions in production and population. A grim picture. But these kinds of perceived connections on flow diagrams are not isolated[2]. We as PRA practitioners know and have repeatedly documented the inter-connectedness of people's lives. We understand how all these things link together. So how should we respond? We need to acknowledge that AIDS is a part of the whole picture and needs to be addressed as such. Otherwise, as many parts of the world are now witnessing, the most economically productive members of communities will die out.

· In this issue...

The four papers presented here highlight some of the exciting contributions which participatory approaches can make to HIV work in Africa and in Asia.

Ssembatya et al. write about their work in south west Uganda. This paper shows how effective PRA can be in enabling community members to recognise the relevance of various aspects of their lives to the spread of HIV. Through a variety of mixed and single-gender group activities, the authors enabled people to recognise when they are most vulnerable to HIV infection. The women and men remarked on the usefulness of what they had learnt, as did the staff involved. This new-found knowledge, which included a recognition of the links between money, gender relations and sex, was then used by community members to discuss possible alternative strategies which might reduce the risks of infection.

Dusit Duangsa's article about innovative HIV risk awareness work in Thailand explains how important it is for people to learn *"that they are not passive victims of the AIDS problem, but there are things they can do to prevent, control, and live with, AIDS."* The article describes how PRA AIDS awareness sessions ask people of the same gender, age-group, social or marital status to work together to assess HIV risk for different sub-groups in their community. Through a gradual process of discussion, division and linking, participants grow to recognise that all members of their community, themselves included, are in some way at risk from the virus. This exercise has been carefully described and clearly has a powerful effect on the participants. As Dusit points out in the conclusion, this is, of course, only a starting point which then needs to be followed up with a wide range of learning activities. To leave a group with no more than this initial exercise could create more harm, in terms of fear and prejudice, than good. But Dusit is certainly aware of this.

[1] This was conducted in November 1994 by Redd Barna. Trainers were Irene Guijt of IIED and Tony Kisadha of Redd Barna.

[2] See also Redd Barna and IIED 1994 *It is the Young Trees That Make a Thick Forest* for another Ugandan example. For examples from Zimbabwe see Welbourn, A. forthcoming: *PRA, Gender and Conflict Resolution: Some problems and possibilities* in Guijt I. (ed) *The Myth of Community: Gender Issues in Participatory Development*. IIED, London.

Source: PLA Notes (1995), Issue 23, pp.57–61, IIED London

Roger Chamberlain's piece illustrates how communities in western Kenya are being challenged through drama to reconsider their attitudes towards HIV. The acting is used as a tool for exploring different people's perspectives towards traditional practices within the community (such as 'widow inheritance'), as well as towards more recent problems, such as teenage pregnancy. Through drama, actors and audience have a chance to explore different situations. The audience can directly question the motives of the actors, or can take to the stage themselves in their own attempt to handle the situation more effectively. Whilst the acting sessions were initially designed to work with young people, the work team soon found that whole villages flocked to the events. This enabled an invaluable interaction and sharing of perspectives between community members. The drama facilitated a spontaneous shift in the attitude of the audiences. As Chamberlain points out, and as with the work of all the authors contributing to this semi-special issue, it will be interesting to see if and how such attitude shifts are translated into practice.

The last article is also from Kisumu in Western Kenya, where Sellers and Oloo describe the careful strategic planning on which their HIV work is based. Their article explains how the communities with whom they work asked them for counselling and testing facilities. The authors quickly recognised the importance of providing such facilities in a coordinated framework of HIV prevention work, based on the communities own perceptions of all the related issues. This article sets out how they planned and undertook five-day exploratory sessions in each village. Once more, issues around access to and control of money between partners were perceived to influence STD and HIV transmission. And once more, the authors state *"villagers feeling powerless... is giving way to a feeling that they can take on the responsibility and actually do something to change the situation."*

· HIV and PRA: contradictions or synergies?

One thing which has struck me about good HIV workers is how much they have learnt to challenge their own beliefs, attitudes and practices in the process of becoming good listeners, communicators and facilitators. They have had to do this to develop the trust of those with whom they are working. Those of us involved in general development work have rarely faced the need to do this in the way that HIV workers have. There is much that we can learn from them about this. At the same time, however, HIV workers often face the challenge of addressing an issue which communities rarely want to discuss, let alone prioritise. How do we introduce a subject that is usually not a perceived need? Surely this contradicts all that good PRA has taught us about putting community groups' priorities first?

I believe that the use of PRA has tremendous value here. Communities are already fully aware of the inter-relationships between gender, economics, power and sexual health. If HIV workers or general PRA practitioners elsewhere ask communities the right questions, similar maps, seasonal calendars, flow diagrams and other charts could be produced in abundance. Sexual health is always an issue in every community and, though they may not be explicitly aware of it until they start to address it in this way, people very quickly describe how it links to so many different aspects of their lives. All that the facilitators then need to do is to add..*"and what about HIV?"* The communities can then already begin to see the potential impact of HIV for themselves, as they look again at their own diagrams. And as we have seen from the articles here, in communities where HIV is already of some concern, PRA can also play a central role in empowering them to take control of the situation.

In conclusion, we hope that you find these articles stimulating and we look forward very much to receiving your comments and accounts of your own experiences. If we receive enough articles, we would hope to have another semi-special issue on HIV and AIDS. Let's make it soon!

- **Alice Welbourn,** c/o IIED, 3 Endsleigh Street, London WC1H ODD, UK.

FURTHER READING

If you are a PRA practitioner wanting to learn about AIDS, here are a few good references:

AIDS Action: a regular newsletter, published by AHRTAG, at Farringdon Point, 29-

Source: PLA Notes (1995), Issue 23, pp.57–61, IIED London

35 Farringdon Road, London EC1M 3JB, UK. Free to developing countries.

AIDS is Our Problem, in six parts. Arid Lands Information Network, 1993 and 1994. Available from ALIN, Casier Postal 3, Dakar-Fann, Senegal. Cost £1 each. £6 for the set.

Living with AIDS in the Community: A small booklet outlining basic facts about HIV and AIDS, which also corrects some common misunderstandings and false assumptions about the virus and its transmission. WHO Global Programme on AIDS. 1992. Based on work done by TASO, Uganda. Free to developing countries.

Strategies for Hope: a series of booklets and videos about good AIDS prevention, care and support programmes in different parts of Africa and Thailand. The next booklets in the series will be about Ivory Coast and India. Available from TALC, at PO Box 49, St. Albans, Herts. AL1 4AX, UK.

Talking AIDS: A guide for community work. IPPF. Macmillan. 1988. A guide for those wanting to develop AIDS prevention work. Cost £2. IPPF, Regents Park, London, NW1 4NS, UK.

The AIDS Home-Care Handbook: A large manual. WHO Global Programme on AIDS. 1993. Based on work done by organisations in Uganda and Zambia. Free to developing countries.

Source: PLA Notes (1995), Issue 23, pp.57–61, IIED London