



ICW VISION PAPER 5

Participation and Policy Making: Our Rights



Participation and Policy Making: Our Rights

ICW believes that when HIV positive people are involved at all levels of decision-making of an organisation, it is better able to respond to the concerns of people living with HIV/AIDS. Moreover, exposure to women, men and children living with HIV has a profound impact on attitudes to people living with HIV as well as knowledge of safer sex (Paxton 2002). To promote our rights and to tackle the HIV/AIDS epidemic effectively, HIV positive women need to be taken seriously by policy makers. The best way to challenge stigma and discrimination is to promote solidarity with and involvement of HIV positive people in all levels of decision making, and to ensure this includes women. Although there is a lot of rhetoric about challenging the stigma of HIV, few organisations take this obvious step.

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Governments must be more responsible from the day they assume power. How can they use the word solidarity when they do nothing to improve things? Why do we sign papers and not act! The problem of AIDS could be solved now, but the commitment has to be there. When HIV positive people claim their rights, don't play the fool with us! We people living with HIV, women, children, men, people with different sexual orientations, are citizens and human beings. HIV is not a health problem, it is a social problem. (Participant from Guatemala in Voces Positivas, ICW 2004a)

The 1982 UN Declaration of a Programme for Action and the 1994 Paris Principle of Greater Involvement of People Living with HIV/AIDS (GIPA) both uphold the rights to inclusion and the strengthening of organisations of people with disabilities and with HIV in all decision-making processes affecting our lives. However, in ICW's experience policy-making bodies are far from ensuring that this principle is met, let alone making sure that HIV positive women are an integral part of any policy development.

Like me, if you want to be employed [by the government], I will send in application forms and after that maybe they will require to take my blood sample. If the results are positive they will say there is no work and they will not employ me, although there is work. So they should involve people living with HIV in all sections by employing them, by giving them work. They should understand that HIV is not transmitted by working with someone. In fact by working with them it is where they get encouraged and will not want revenge. (Participant of Kampala conference 2003¹)

Involvement in national policy making and in regional and local structures is one important arena of policy making. But it is not the only arena that needs to be more open to the views and involvement of HIV positive women and our networks. Others include faith-based institutions, the private sector, trade unions, women's organisations, mainstream AIDS organisations, employers' organisations, political parties, non-governmental and international organisations and educational institutions.

¹ 11th International Conference of HIV Positive people, Kampala, Uganda, October 2003



We all also have to be aware that women from different social groups face greater and/or different barriers to making our voices heard.

At present young women are less empowered and more disadvantaged. To achieve the goal, young women living with HIV and AIDS have to be empowered in order to ensure that their voices are heard and that they are seen as an integral part of any solution. (ICW Young Women's Dialogue, 2004)

HIV positive women activists have responded to the lack of involvement in other organisations, and the lack of support for and continuing discrimination towards HIV positive women. Initially we formed support groups in our communities, throughout the world, that have provided the basis for a shared understanding of inequality and rights (Manchester 2003). This environment of mutual support has given us the confidence and skills to challenge the power of others to make decisions over matters that affect our lives.

At first, we went into our advocacy work with our faces covered because it was too dangerous to let anyone see us. It would have been impossible not only for us, but also for our families and children. [...] In the end, though, we started to disclose and to give our names out. You can't hide forever, and we should not have to. (Founder of REVS+, ICW 2004b)

However problems remain when HIV positive women try to change other organisations:

We have worked tirelessly to get our views onto the agenda and represented in decision-making arenas of all types of institutions. However, external agencies often fail to realise the burden on individuals of being asked to speak without adequate support. This can result in exhaustion and

difficulties in balancing family and work responsibilities and complicated treatment regimes. (Manchester 2004)

Our networks should be a vital source of information and ideas for policy makers. Yet policy-makers often ask HIV women to attend meetings just to add on a personal story to set the scene only, or at the end of real policy debate and development, from which the HIV positive speakers are excluded. In fact policy making circles are generally 'closed boxes', staffed by select 'experts' that may have little understanding of social inequalities, or of rights and how to realise them. The results of consultations aimed at feeding into policy too often get dropped from the agenda. Yet these consultations are cited as evidence that policies are inclusive.

We're weary of being asked to attend meetings as an after-thought, to stand up and provide a personal testimony but little else, [...] The issue of 'how I got infected' matters far less than 'what I did next'. We want to be included from the outset in deciding agendas, taking decisions and ensuring their implementation. (Roberts 2004).

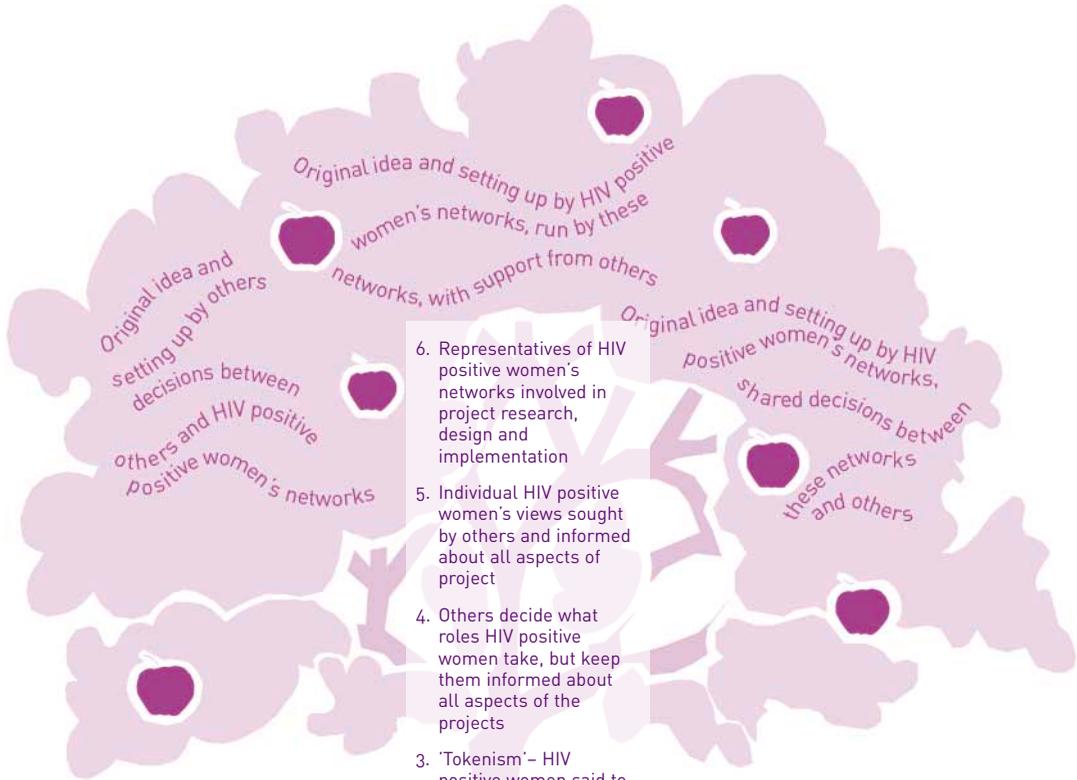
How participatory is your work and organisation?

Overleaf you can assess where organisations you know of are in relation to the involvement of HIV positive women's organisations, including ICW, by using the idea of a 'participation tree'. Near the base of the trunk, decisions are made solely by others. Women and girls living with HIV have no role in decision making. Further up the trunk, decisions are made by others with advice from HIV positive women. At the top of the tree, where you will find the fruit, there is more sense of real partnership between HIV positive women and our organisations, and others.



Where do you think your organisation's work fits on this tree?

Is your work bearing good fruit?



6. Representatives of HIV positive women's networks involved in project research, design and implementation
5. Individual HIV positive women's views sought by others and informed about all aspects of project
4. Others decide what roles HIV positive women take, but keep them informed about all aspects of the projects
3. 'Tokenism' – HIV positive women said to be involved but have no decision making power in how the project is designed
2. 'Decoration' – HIV positive women only put 'on public show' but no involvement in any part of project
1. 'Manipulation' – HIV positive women are used by others to do what others want them to do.

ICW aims to work with our partners at the top of this tree, where the fruit can be found.



(Adapted from Hart 1997)





ICW Call for Action

To fully support the representation and advocacy work that we are involved in and to gain from our diverse skills, experiences and insights we call for policy makers to:

Support the work of HIV and women's rights groups:

- Recognise the skills and experience of HIV positive women and our networks in advancing women's empowerment, and confronting the epidemic effectively.
- Ensure and support the involvement not only of individual positive women but also representation of our networks in all policy making and strategising meetings. This involves ensuring not only a place at the table, but also that our issues are on the agenda.
- Support the capacity building needs of these networks with regard to fund management, strategic planning, and other administrative processes.
- Allow for adequate time to make arrangements for attendance at meetings and offer to pay travel, child care, and accommodation costs.
- Develop your own staff and management capacity to engage in alternative, more interactive and less formal means of consultation and collaborative working, to ensure that HIV positive women and girls who may be less used to formal meeting structures have the opportunity to contribute our ideas fully.
- Develop mechanisms and training to encourage HIV positive women to participate in the electoral process, political activities and other political arenas.

Support the involvement of HIV positive women in your own organisation:

- Actively seek out and employ HIV positive women at all levels of your organisation, and ensure that workplace policies can facilitate this.
- Provide leadership and self-esteem training to assist HIV positive women, particularly those with disabilities and belonging to racial and ethnic minorities and younger women. Such training should strengthen self-esteem and encourage HIV positive women to take decision-making positions in the business community, development agencies, governments, and also within organisations of HIV positive people.
- Have transparent criteria for decision-making positions and ensure that the selecting bodies have a gender-balanced composition.
- Provide gender-sensitive training for women and men to promote non-discriminatory working relationships and respect for diversity in work and management styles.
- Develop ways that will encourage all staff to be more open about their own HIV status.

Our networks should be a vital source of information and ideas for policy makers.



Working towards political rights and participation

Building skills and confidence:

HIV positive women who were team leaders of ICW research in Zimbabwe on women and HIV/AIDS were given training in participatory research techniques as well as taking part in presentations of research results. As a consequence they report greater prominence in their communities. Team leaders in Birchenough Bridge were elected to serve on their local constitutional reform committees. Three have taken up positions on a community working group on health and one has been appointed to her local hospital board to represent people living with HIV (ICW 2002).

Changing organisational structures:

Young women and men now form 25% of each International Planned Parenthood Federation (IPPF) regional board globally, and regional meetings are tailored to suit more dynamic, interactive and less paper driven ways of working. This was in response to IPPF's recognition that, while young people formed a key part of their clientele, IPPF ways of work and decision-making structures consistently excluded young people. Similar approaches could be adopted to ensure inclusion of young positive women by other organisations. www.ippf.org (Faulkner and Nott 2002)

Participation in government and international bodies in Latin America:

HIV positive women have made significant progress in securing some representation in national and international arenas and in getting HIV on to political agendas. Participants of ICW's Voces Positivas training workshops from Costa Rica, El Salvador, Peru, Venezuela, Nicaragua, Guatemala, the Dominican Republic, Honduras and Mexico have participated in national AIDS programmes and The Joint United Nations Programme on HIV/AIDS (UNAIDS) theme groups. Thanks to the activism of HIV positive women Mexico now has a National Commission for Women Living with HIV.

Raising the voices of HIV positive women in all policy making:

ICW has asked UN and other agencies to include ICW in their meetings, rather than only individual positive women, so that ICW can build up this collective knowledge to share with the rest of the membership. The idea behind the ICW group of speakers is to enable us to support individual positive women when they attend meetings. The support we are able to offer includes international background information about the issues which are going to be discussed, so that speakers can talk not just from the perspective of their own experiences, but can also bring the voices of the international community of women living with HIV/AIDS to the table.



Positive women claim the stage: World AIDS Conference, Amsterdam 1992.

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Paxton, 2002, 'The impact of utilizing HIV-positive speakers in AIDS education', *AIDS Education and Prevention*, 2002; 14: 282-294

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Young Women's Dialogue, Southern and East Africa, Durban, 19-23 April 2004

Voices & Choices Zimbabwe and Voices, 2002, and Voices and Choices Thailand, 2003. A project led by positive women to explore the impact of HIV on their sexual behaviour, well being and reproductive rights, and to promote improvements in policy and practise.

Voces Positivas – empowerment and training for HIV positive women from Central America and the Caribbean, 2003



ICW Vision Papers (2004) have been written for HIV positive members and our supporters to use when advocating and organising around ICW's visions, aims, and objectives. In them you will learn what ICW's positions are and be able to represent ICW well at any meetings or in any groups you attend, or if you are asked in any circumstances to explain what ICW stands for. They are meant as an aid to your own work and can be used creatively. ICW welcomes your feedback and evaluation of its vision papers. Please tell us how you have been able to use them. We'd love to hear from you.

This Vision Paper on participation and policy making is one of five ICW Vision Papers. This series outlines ICW's position on: access to care and treatment; participation and policy making, gender equity and poverty; human rights; and HIV positive young women. They are available in English, Spanish and French.

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The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development.

All HIV positive women can join ICW for free. Just contact us – details below.

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ICW is the convening agency for the treatment and care arm of the Global Coalition on Women and AIDS.

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