

The Greater Involvement of People Living with HIV/AIDS: from principle to practice?

by the INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS

Introduction

The International Community of Women Living with HIV/AIDS (ICW) is the only international network of HIV-positive women. ICW envisions a world where HIV-positive women are respected and meaningfully involved at all political levels where decisions that affect our lives are made. Our hope is that with your experience of participatory ways of working, you will respond to this paper with advice, support and engagement on these issues.

In 1994, at the Paris AIDS Summit, 42 national governments declared that the principle of Greater Involvement of People Living with or Affected by HIV and AIDS (the 'GIPA principle') is critical to ethical and effective national responses to the pandemic. While the GIPA principle is widely accepted in theory, our experience is that the views and voices of HIV-positive people still tend to be overlooked or ignored. GIPA is a useful mobilising device to rally around but no strategy was put in place to secure effective involvement. Furthermore, the principle was never gendered. It has proved hard for HIV-positive women to have their voices heard, and harder still for young HIV-positive women and others who are more marginalised, such as sex workers, positive women prisoners and injecting drug users.

Meaningful implementation of the GIPA principle is not

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simply about seating HIV-positive women at decision-making tables where a mandatory space has been created; it is also about us setting the agenda. It is not only vital that HIV-positive women with the skills and capacity to make decisions are involved as equal partners – but that those in positions of power learn to engage with us in ways that are inclusive and respectful, or else our involvement becomes tokenistic.

Both the technical and personal experiences of our members demand that they be involved at every level of the development, design and delivery of sexual and reproductive health, treatment and care services for HIV-positive women and girls around the world. To ensure 'services to fit women' (rather than 'women to fit services'), groups and individuals concerned with these issues must work in creative, interactive and participatory ways with HIV-positive women, as well as with others who work directly with community members

and other relevant groups. Only through such collaborative efforts can we adequately address the barriers that prevent women and girls from accessing these services.

Here, we discuss:

- our struggle to ensure that all our members' voices are heard in our advocacy efforts;
- the gendered barriers to greater involvement; and
- the resulting tendency for organisations, institutions and networks (including ours) to 'cherry-pick' and 'gatekeep' when it comes to involvement.¹

This article draws on experiences from our members' involvement in many processes over the years. We share such experiences through our newsletter, members' e-forum, during our advocacy development and training workshops, and in informal exchanges between members.

Our issues don't get discussed

HIV-positive women's issues are often excluded in national, regional and local mainstream dialogues. The following quotes from HIV-positive women who have taken part in programme and policy initiatives illustrate the exclusion of their experience during design, planning, and implementation.

Our input is not implemented, and our ideas are not taken into consideration.

We have organisations, but men lead them, and our issues don't get discussed.

Policy makers sit in boardrooms and decide what is relevant to our lives – we are not part of the process.

This ongoing marginalisation of HIV-positive women is not only a feature of mainstream policy arenas. HIV/AIDS organisations do not adequately take into account the perspectives of women and reflect the patriarchal norms of societies at large. Despite women's strong leadership in support groups, we find that national, regional and international organisations and networks of people living with HIV and AIDS are dominated by men. Too many NGOs and civil society groups working on HIV see themselves as caretakers

and advocates for HIV-positive women, leaving us to assume that they do not think we are empowered or responsible enough to think or advocate for ourselves.

Women are used for their experience, but because the woman is not very educated they think that they need professionals to decide on things. (ICW member, Tanzania)

One World Bank officer once said at a meeting, 'We can't involve representatives of HIV-positive women's networks in our meetings because they don't know how to behave in them.' (ICW member)

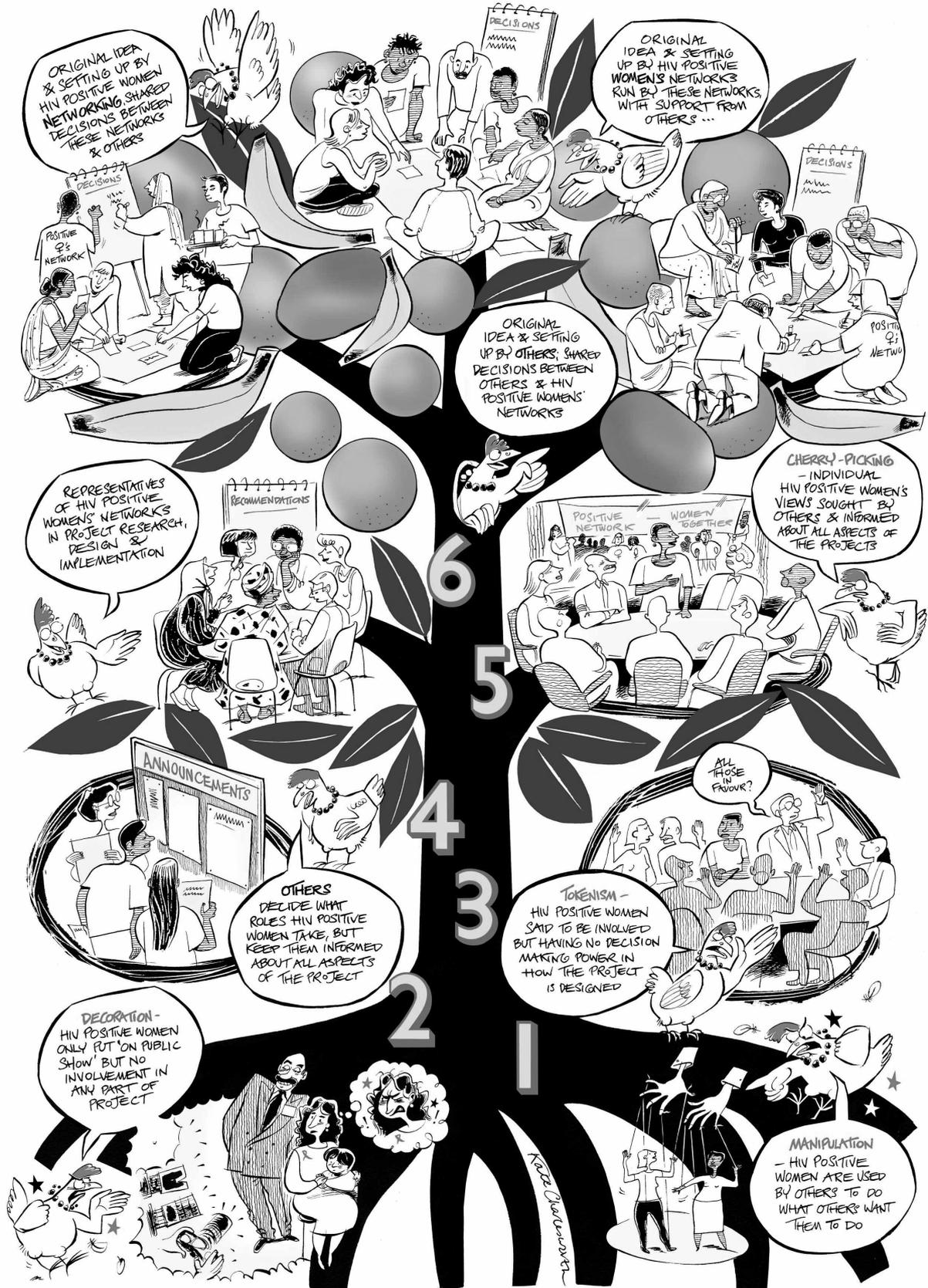
Issues important to us are often not seen as important by people not directly affected by HIV. Our daily experiences starkly reveal the barriers to achieving our rights both as women and as people living with HIV and AIDS. These experiences can give us insights and knowledge which, if ignored, may well reduce the positive content and impact of work around HIV and AIDS. It is not impossible for people who are HIV-negative or who may not know their status to support us and understand our issues. But any decision-making forum on HIV that does not involve HIV-positive women who represent positive women's networks is missing a vital perspective representing a body of 'expertise by experience'.

ICW has identified a real need for safe spaces, and for research and advocacy development projects specifically run by and for HIV-positive women from different backgrounds or with different experiences and lifestyles. We have developed specific projects with young positive women, and HIV-positive women who are or were injecting drug users. However, outside ICW a frustration for us is that 'women' (or 'gender') is generally seen as one category, differentiated from, for instance, injecting drug users, prisoners, or young people. This implies that HIV-positive women prisoners, for example, have the same experiences and priorities as HIV-positive male prisoners. For women who are already marginalised such as sex workers, mobile populations, prisoners, injecting drug users and young women, the additional marginalisation of their HIV-positive status can silence their voices. Even within activist circles our young members do not feel their concerns are taken seriously by older members. Similarly, ICW members who inject drugs have struggled to get their voices heard either by HIV-positive non-injecting drug users or HIV-positive male injecting drug users.

Increased involvement needs to be qualified in terms of type and quality. Yet policies and guidance papers on HIV

¹ **Cherry-picking** is the act of pointing at individual cases or data that seem to confirm a particular position, while ignoring a significant portion of related cases or data that may contradict that position. Source: http://en.wikipedia.org/wiki/Cherry_picking. **Gatekeeping** is the process through which ideas and information are filtered for publication. Source: [http://en.wikipedia.org/wiki/Gatekeeping_\(communication\)](http://en.wikipedia.org/wiki/Gatekeeping_(communication))

IS YOUR ORGANISATION



ORIGINAL IDEA & SETTING UP BY HIV POSITIVE WOMEN NETWORKING SHARED DECISIONS BETWEEN THESE NETWORKS & OTHERS

ORIGINAL IDEA & SETTING UP BY HIV POSITIVE WOMEN'S NETWORKS RUN BY THESE NETWORKS WITH SUPPORT FROM OTHERS ...

ORIGINAL IDEA & SETTING UP BY OTHERS, SHARED DECISIONS BETWEEN OTHERS & HIV POSITIVE WOMEN'S NETWORKS

REPRESENTATIVES OF HIV POSITIVE WOMEN'S NETWORKS IN PROJECT RESEARCH, DESIGN & IMPLEMENTATION

CHERRY-PICKING - INDIVIDUAL HIV POSITIVE WOMEN'S VIEWS SOUGHT BY OTHERS & INFORMED ABOUT ALL ASPECTS OF THE PROJECTS

ANNOUNCEMENTS

OTHERS DECIDE WHAT ROLES HIV POSITIVE WOMEN TAKE, BUT KEEP THEM INFORMED ABOUT ALL ASPECTS OF THE PROJECT

ALL THOSE IN FAVOUR?

TOKENISM - HIV POSITIVE WOMEN SAID TO BE INVOLVED BUT HAVING NO DECISION MAKING POWER IN HOW THE PROJECT IS DESIGNED

DECORATION - HIV POSITIVE WOMEN ONLY PUT ON PUBLIC SHOW BUT NO INVOLVEMENT IN ANY PART OF PROJECT

MANIPULATION - HIV POSITIVE WOMEN ARE USED BY OTHERS TO DO WHAT OTHERS WANT THEM TO DO

BEARING FRUIT?

THEME SECTION 3

Cartoon: Kate Charlesworth

rarely qualify GIPA. These policies remain rhetorical and often satisfy themselves with the inclusion of HIV-positive women as research respondents or service recipients.

People sign up to GIPA without knowing the meaning of GIPA – they do it to get funding. (ICW member)

Such experiences with GIPA have led people to speak about MIPA – **meaningful** involvement of people living with HIV and AIDS, and even MIWA – meaningful involvement of **women** living with HIV and AIDS. Yet whatever it is called, if organisations working on HIV do not have a clear idea of what we mean by ‘meaningful’ we will continue to be used to legitimise exclusive processes of engagement. ICW produced a poster depicting a continuum of involvement moving from manipulation and tokenism to what we then considered to be more meaningful forms of involvement, e.g. the setting up of networks by HIV-positive women (see Figure 1). However, we now realise our poster misses a more political view of GIPA whereby HIV-positive women hold governments to account in terms of what they are doing to uphold the rights of HIV-positive women and what a healthy relationship with policy makers would look like.

Last year I was invited to speak about GIPA and stigma and discrimination at UNGASS.² The government of x organised a meeting for all the delegates from x and told the delegates what they should say [...] I was criticised and put aside for making a big noise and being critical about the government. (ICW member)

We have also noted how we shape our argument to get our message across. For example, HIV-positive women activists often use the gender inequality argument rather than a direct rights-based argument to gain recognition of the importance of their sexual and reproductive health and rights (SRHR) (see Box 1). The inequality arguments are powerful and ICW makes reference to these over and over again.

Many HIV-positive women get HIV in their marriage beds. Women often cannot negotiate safe sex.

² UNGASS refers to the United Nations General Assembly Special Session on HIV/AIDS, 2001 at which a Declaration of Commitment on HIV/AIDS was made. Regular review meetings are held to monitor progress towards the commitments made.

Box 1: Sexual and reproductive health and rights

- **Sexual health:** Includes healthy sexual development, equitable and responsible relationships and sexual fulfilment, freedom from illness, disease, disability, violence and other harmful practices related to sexuality.
- **Sexual rights:** the rights of all people to decide freely and responsibly on all aspects of their sexuality, including protecting and promoting their sexual health, be free from discrimination, coercion or violence in their sexual lives and in all sexual decisions, expect and demand equality, full consent, mutual respect and shared responsibility in sexual relationships. We also have the right to say ‘no’ to sex if we do not want it.
- **Reproductive health:** The complete physical, mental and social well-being in all matters related to the reproductive system including a satisfying and safe sex life, capacity to have children and, freedom to decide if, when and how often to do so.
- **Reproductive rights:** The rights of couples and individuals to decide freely and responsibly the number and spacing of their children, to have the information, education and means to do so, attain the highest standards of sexual and reproductive health and, make decisions about reproduction free of discrimination, coercion and violence.
- **Reproductive care:** Includes, at a minimum family planning services, counselling and information, antenatal, postnatal and delivery care, health care for infants, treatment for reproductive tract infections and sexually transmitted diseases, safe abortion services where legal and management of abortion-related complications, prevention and appropriate treatment for infertility, information, education and counselling on human sexuality, reproductive health and responsible parenting and discouragement of harmful practices. If additional services, such as the treatment of breast and reproductive system cancers and HIV/AIDS are not offered, a system should be in place to provide referrals for such care.

Source: ICW factsheet, adapted from definitions of SRR from the programme for action resulting from the International Conference on Population Development (ICPD), 1994.

Women are dependent on men so they cannot assert their reproductive choices.

We have a hard time simply getting these facts recognised and addressed. Yet, significant as they are, it is only half the story. Some of these messages can over-emphasise women’s victimhood. They do not address the fact that women also have sex outside of marriage, can choose to have unprotected sex, or get pregnant by choice. ICW wants to see the sexual and reproductive rights of all HIV-positive women respected. However, we are caught between feeling that gender inequality arguments are somehow seen as ‘old hat’, and an HIV/AIDS policy context which prefers to avoid the language of rights, particularly sexual and reproductive rights.

Who represents who and what?

ICW is frequently asked to provide ICW women advocates or to speak at international meetings with the aim of feeding into policies and programmes. These invitations raise a number of questions, which are discussed further below.

- How can we train up less experienced HIV-positive women to take on advocacy roles at international levels, and avoid creating a situation where only a select few have access to the policy-making arena?
- How can we ensure that ICW representatives are effective, feel supported and are able to present their experience as well as the collective ICW perspective and a clear agenda for change?
- Why do already skilled and experienced activists often prefer to 'go it alone' rather than attend such meetings as a linked 'representative' of a network of HIV-positive women?
- The bigger question is, do we even want to continue engaging with policy processes which only open their doors to a select few?

We have not sufficiently challenged definitions of 'positive leadership', which contribute to empowering a select few as global advocates and leading lights, in an individual capacity, and at the expense of the many. We are therefore complicit in creating an 'aidserati' (a global HIV elite), cherry-picking and gate-keeping so that the same faces and names remain on the circuit to the exclusion of others.

They call their friends or people that they know. (ICW member, Tanzania)

One way ICW is trying to address this is through a programme working with young HIV-positive women to develop their advocacy and policy-influencing skills, knowledge and plans. We have run young women's dialogues (YWD) in Southern Africa, South Africa, Swaziland and Namibia. Originally using a training workshop format, we now build in ongoing support for up to a year to allow the women to develop their skills and implement their plans after the initial workshop. We also encourage seasoned activists to mentor less experienced activists.

However, we need to ensure that we are not just fostering a new elite without really challenging the way that policy making is done and the way that positive people are used to legitimise largely exclusive and restrictive policy processes. Do we want to be present at all if our involvement is purely about legitimising others' agendas?

We also need to ensure that our representatives are

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accountable. How do we, and they, ensure that their individual experiences, perspectives and concerns represent those of other HIV-positive women? Should we even expect them to put forward the views of others? And how do they communicate their advocacy experience back to other women? In situations where ICW is asked to identify a person to be part of a forum where policies or strategies are being devised, we need to ensure that they speak from ICW's perspective, aims and politics. Yet we have yet to articulate clearly how this could happen, or even what this would involve, given that ICW is a network with a membership with such diversity of individual experience. Positive women representatives tend to be invited to decision-making fora at the last minute and this further reduces the scope for advance consultation with other HIV-positive women. Such consultation is vital, however, because it enables women to get involved without publicly declaring their status – which many women are reluctant to do.

If GIPA is a conditionality of funding, then people living with HIV need to have a voice in the process – and this needs to be confidential – not just being put on display for the donor to see. (ICW member)

Organisations for people living with HIV/AIDS are underfunded and their input undervalued. Positive representatives at the policy table are usually there as volunteers. Our attendance is dependent on funding by policy makers and often only out-of-pocket costs are covered. This makes it difficult for anyone in work to take on such a role. It also creates an uncomfortable imbalance when we are around a table with people representing other bodies who are on full-time salaries. Many activists rely heavily on the per diems they get from attending events and workshops run by other organisations. This can create resentment from other activists when they see the same people going to events again and again. If organisations are really committed to ensuring that HIV programmes are successful then adequate funding should be

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available to make sure that our time and energy is compensated for.

Policy making environments can be quite intimidating and we often find ourselves the ‘lone voice’ of HIV-positive women.

I sometimes find I am the only HIV-positive woman at a high-level forum. (ICW member)

We spend weeks away from loved ones, often unpaid, sitting around big tables, our input strictly limited when, for example, we are designated as observers only or are not given a specific slot for speaking. We do this on the off-chance that we can have some influence within parameters that have already been determined. Much decision-making is done in the ‘corridors of power’ rather than in meetings to which we are invited. Perhaps policy makers should spend some time with our members in the environments where **they** live, and learn from them how to be more inclusive. Too often, our lack of capacity is used as an excuse not to include us, when in fact those that currently make the policies need to think about **their** capacity to engage with us.

We need to look at ways of engaging in processes that lead to positive change in our lives. They may involve mentoring, sharing, building networks, and creating dialogues and accountability so that groups of people feel their voices are represented, even when they are not physically present at meetings. This must not occur as a one-off, but involve continuity and two-way dialogue. Our challenge is that our members are spread broadly across the globe, many with little access to information communication technology (ICT). At ICW we are continually trying to adapt, develop and experiment with more inclusive forms of representation. We would welcome ideas from other organisations and networks on their experiences.

ICW’s membership reflects in many ways the diversity of women’s lives in general. All HIV-positive women can, with encouragement, relay their experiences of living with HIV and feel solidarity with other HIV-positive people around the

world. The impact of ‘telling’ truths and illustrating barriers to sexual and reproductive health through personal stories can be powerful. It can help influence policy makers to understand and take on board the reality of living with the virus. This can be one important element of GIPA and one which demands as much respect and attention as any other – when it is not exploitative, and used with full sensitivity to the personal issues it may raise.

However, there are additional levels of skill, capacity and political sophistication which are needed in any meaningful application of the GIPA principle. We want the expertise and political sophistication of a growing number of us to be recognised and respected.

In Namibia, for example, we have set up the 13-member Namibia Women’s Health Network. It is made up of mainly HIV-positive (12 of the 13) young women.³ The project is empowering these women and four female Members of Parliament through a series of trainings, which include sexual reproductive health and rights.

Being part of the network and working with other positive women – it has made me realise that I am not alone and there are other people like me. It has released that inner person and psychologically I am no longer that stressed and oppressed. (ICW member from Namibia)

The 13 women will be linked with MPs and a committee of 26 women, who are being selected from the 13 regions (two women – one older and one young woman – from each region), who will monitor services and talk to community members to bring important issues to the policy makers. The project wants to ensure that HIV-positive women are meaningfully involved in making decisions, including national policies, that impact on their lives. Through training parliamentarians, we hope to build the capacity of those in positions of power to engage with HIV-positive people in ways that are equitable, respectful, and productive for all involved.

Now they have the committee to work with. Now we can see that we have a point where we can channel our concerns. Before when you spoke about MPs they were distant and it was difficult for a community to imagine reaching them. (Member of Family Hope Sanctuary in Namibia)

³ A similar approach has been applied regionally by ICW Latina for the past four years (ICW News 25, 2004).

This example from Namibia does not entirely do away with the problems of selection and representation. But it does build into its workings a commitment to consult and liaise with communities. Organisations need to recognise that when they do not involve us in ways that are respectful and meaningful the quality of programmes and policies suffers and their impact is lessened. The longer we wait to involve HIV-positive women, the more time is wasted in addressing the challenges around HIV faced by countries and communities. We realise that our efforts to move organisations from

tokenistic to meaningful behaviour may make us unpopular (particularly when organisations seek to work with us so that they can tick the right boxes). This is partly because it involves HIV-negative women and men questioning their own role in tackling this pandemic and partially because we are often working with organisations with more resources and power than we have. We are not just asking others to think about this issue – we are asking everyone to ask themselves: What am I doing, and what is my organisation doing, to meaningfully involve HIV-positive women?’

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