

GENDER AIDS FORUM

Putting Women at the Centre: Critical challenges in effective responses to HIV/AIDS

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The way in which we define a problem determines how we approach its solution.

It is time to replace the notion that HIV is just a virus whose spread is affected by risk factors and biological co-factors with a broad concept of vulnerability to heterosexual HIV transmission. This shift will entail augmenting our existing strategies for prevention with programmes and policies that address the central inequalities underlying vulnerability to HIV and AIDS.

Jonathon Mann

Women and girls in South Africa are faced with daily hardship on both a physical, social, emotional and economic level. The unequal power relations between men and women – impacting at a personal, relationship, household, community and societal level - is a key factor in the deepening impact of HIV and AIDS in the region. Whilst policies may exist to advance and improve the position of women and girls in the country, and some women may have benefited from policy change, the actual realities of most ordinary women's lives have not improved significantly. Given the context of HIV and AIDS, and an already massive burden of poverty, the position of women and girls is declining with a threat that gains made in terms of narrowing the gap between women and men, boys and girls, are being or will be eroded.

Despite almost 20 years of experience of HIV and AIDS globally, young people, especially young women, remain vulnerable and infections continue to rise. Women now make up half of people living with HIV/AIDS globally, and 58 percent in sub-Saharan Africa. The numbers of young women living with HIV is even more worrying - in 2000 there were an estimated 8 600 000 young people living with HIV in sub-saharan Africa, 67% of which are women. In some of the hardest hit countries of southern Africa, young women are 5 to 6 times more likely to be infected than young men in the same age group.

The reasons for women's vulnerability is well documented and include biological, social, political and economic factors [see Agenda 39, GAF training manual]. The vast majority of infections occur sexually. Young women have little power when it comes to deciding when, with whom and how to have sex - without power women are likely to experience little control over sexual relations with men. A lack of control over their own bodies and sexuality increases their vulnerability to HIV, STI's and pregnancy. **However, it is within the context of unequal power relations that women are required to take preventative and protective actions aimed at minimizing their risk of contracting HIV.**¹

The last decade has seen a mushrooming of responses to HIV/AIDS at an international, national and local level. Whilst there are growing expressions

¹ Travers and Bennett, 1999: p67.

of commitment to addressing the gender dimensions of HIV/AIDS, action at a policy and practice level still needs development. The effectiveness of the response depends on the ability to deal with the many inequalities that are driving the epidemics.

This paper presents some of the critical challenges identified by my personal experience as well as the experiences of the Gender AIDS Forum in attempting to come to grips with gender. Many NGO's and CBO's have heeded the call to address gender inequality and oppression as central to the response to HIV/AIDS and are grappling with HIV issues and gender. My interaction with them has informed my thinking and their efforts are acknowledged. After years in the field of HIV/AIDS it is essential to state that addressing gender and AIDS in a meaningful and effective way is not easy. We must realise that in essence we are addressing centuries of women and girls oppression, and that this oppression is coloured by other oppressions on the basis of class, religion, culture, sexual orientation. Women have made strides over the centuries – politically, economically and socially. However, the place that gender and HIV/AIDS intersect most fundamentally is in the home, in the relationship and it is here that men's power is strong, and cultural values about women's sexuality most pronounced. Thus, we have a huge task ahead to transform personal and sexual relationships between men and women, but we can and will succeed by working in solidarity with others. ■

This paper will:

- Provide a brief history of the response to addressing women/gender and HIV/AIDS
- Provide an example of how our responses do not match our analysis
- Focus on three critical challenges:

Placing women at the centre – how do we ensure that we address the realities of women's lives and increase participation

What does power mean

Shift from gender aware to empowerment and transformation

ADDRESSING GENDER AND AIDS: A BRIEF HISTORY

“Women’s history in the epidemic was one of unrelenting marginalisation”
[Patricia Flemming, US Government spokesperson quoted in Stoller 1999, p 11]

In 1981 the world was alerted to a new disease which was thought to only affected gay men. Whilst the number of gay men identified as having GRID [Gay Related Immune Deficiency – was only later redefined as AIDS] increased so did the prejudice, hatred and fear. The lesbian and gay community mounted a response to try and prevent the further spread of HIV and importantly to provide care and support, allowing men to die with dignity which was not possible in hospitals and health care facilities due to the high levels of stigma and discrimination. This is the history of the epidemic that most people know – and the myth that only gay men get AIDS is still prevalent.

What people do not know is that the first diagnosed case of AIDS in women was recorded as early as 1982 – and it is possible that women died of AIDS related illnesses prior to this but it was not detected. The numbers of women infected continued to rise in the 1980’s – especially in the South but also in the North. However, despite the fact that HIV did not discriminate on the basis of sex, sexuality or gender, women’s vulnerability was not highlighted nor was it addressed. Women across the world went through the 1980’s not knowing that they were at risk for HIV infection.

When women did step into the spot-light the focus was on female sex workers blamed for the spread of HIV. Sex workers were the bridge population – taking HIV from the “deviant populations” into the general population. Sex workers, like gay men were already on the margins of society, and with the added burden of being held responsible for the heterosexual spread of HIV faced further stigma and discrimination. Unlike gay men, sex workers had far less access to resources, and whilst some organised sex workers developed successful prevention programmes the same level of care and support programmes for sex workers by sex workers was not possible.

For the first time in a decade of the epidemic the global focus was on women and the theme for World AIDS Day 1990 was Women and AIDS. This had little real effect and women’s concerns were [and one could argue still are] not fully addressed. However, there was a groundswell of women’s voices – putting women’s issues and the issues of women living with HIV on the predominately male agenda – women fighting to have their issues recognised and tackled. The International Community of Women living with HIV and AIDS was established in 1992. In the same year the women’s caucus, consisting of women activists involved in HIV and AIDS, started challenging the International Conference agendas which reflected the global priorities in the response to HIV and AIDS and which omitted to see women’s issues and gender inequalities as central.

This growing acknowledgement that women were also affected by HIV and AIDS was not always positive. The blame shifted solely from female sex workers to women in general. Women were put into two categories – “the innocent victim” or the “vectors of transmission” - those women who

infected their male partners and their children. Even now, in the third decade of the epidemic women, [often the first to know their HIV status through their own health, pregnancy, or the health of their baby], are still blamed for the epidemic. Greater recognition of women's vulnerability did not, and still has not, led to a sufficiently effective response.

In South Africa the history of the epidemic follows similar paths to that in other countries: whilst the first people to be diagnosed as having HIV infection or AIDS were gay men, women were not far behind.

Some critical milestones in the South African response to dealing with women/gender and HIV/AIDS:

1992: The Medical Research Council held a meeting focusing on women and AIDS: From sexuality to seroprevalence, from counselling to care. This meeting consisted mainly of researchers and a few practitioners the aim being to identify gaps in research and begin to generate ideas to fill them. The central theme was the "need to know more about the areas over which women do have some control and very critically we need to understand much more about how men use their power". Whilst the meeting was good there was not much evidence of how this translated into subsequent action

1994: The NACOSA plan.

Born out of an extensive provincial and national consultative process the NACOSA plan cited gender as a key principle and attempted to mainstream gender into all the strategies.

1997: The National Review of the response to HIV and AIDS in South Africa - gender as after thought.

The review process involved teams of international "experts", national and local government and non-governmental role players and people living with HIV/AIDS visiting all 9 provinces to assess the response to date. The teams came up with critical challenges – gender as an issue was not reflected. Once the document had been completed a few paragraphs on gender were inserted.

1998: Gender consultant appointed to National HIV/AIDS Directorate

A group of consultants were appointed by the Directorate on 18 month contracts to address critical issues, including gender. After the 18 month period permanent positions addressing all the issues except gender were put in place.

1998: Agenda

In 1998, Agenda [a South African feminist journal] were approached by JOHAP to join forces with gender activists and AIDS activists to produce an edition of the journal highlighting the critical gender issues in relation to HIV and AIDS. The outcomes of this partnership included the identification of gender issues driving the HIV/AIDS epidemic, a South African analysis of the epidemic focusing on women and the birth of the Gender AIDS Forum [GAF] to take forward the learnings and ensure that women and AIDS organisations work together.

The edition of Agenda raised many important issues and challenges. These challenges were aimed at government and civil society and were an attempt to get organisations to take seriously the threat of HIV and to see HIV as a crisis for women.

It is now five years on and little has changed. Whilst more and more institutions and organisations are sensitive to HIV and AIDS and the links between gender and AIDS, this is not reflected in the response to HIV and AIDS which is more of the same. In this way we are making little impact in reducing vulnerability and impact.

The big question is do we **really** know what to do?

BEYOND WORDS: WHAT IS BEING SAID AND WHAT IS BEING DONE?

What is clear from the many writing and programmes on HIV and AIDS that there is an acknowledgement of gender inequality as a driving factor in HIV transmission. Furthermore it is also acknowledged that women are more affected and have to carry the heavy care and support needs of people living with HIV/AIDS in their families and communities. This understanding of women's vulnerability to HIV and AIDS does not necessarily mean that we integrated this knowledge or that our knowledge informs our work.

Let us look at an example:

What we know and say:

Women are more vulnerable to HIV infection.

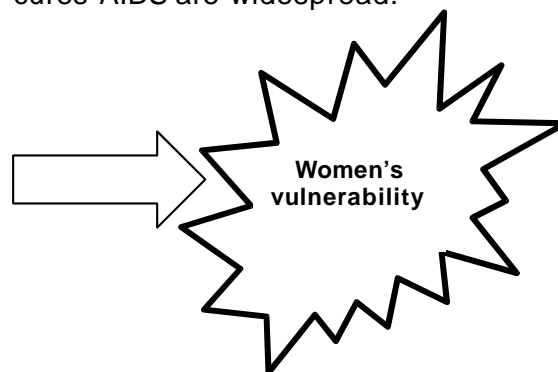
Women have little control over their sexuality – especially when it comes to insisting on safer sex practices.

Men control when, where and how sex takes place.

Girls and young women are especially vulnerable and may be coerced into having sex with older men.

Myths such as sex with a virgin cures AIDS are widespread.

Economic dependence
Cultural practices
Women's lack of sexual decision making
Coerced and forced sex
Sugar daddies
Myths



What we do

Promote messages of abstinence, be faithful and condomise [for this read MALE condom].

Place the responsibility on young women and girls to remain virgins and HIV negative. We test girls and women to see if they are virgins in public ceremonies and identify the virgins to the community.

Focus our prevention efforts on men – as the ones with the power but have no sanctions for older men who “rape” or have sex with younger women and girls.

Note: These messages will not address the deep seated problems we have identified that increase women's vulnerability to HIV infection. We need a more realistic, holistic and multi-pronged attack

What we could do:

Develop a two pronged approach that addresses the ROOT causes, or structural causes of women's oppression as well as addressing the short term goals that will make a difference.

Approach one: The long term

Access to power is at the centre of women and girls vulnerability to HIV and AIDS. Women need to empower themselves, reinvent power and transform society. This will be discussed in greater detail in the section on critical challenges

Approach two: The short to medium term

- Re-define prevention messages that are appropriate to the lives of men, women, girls and boys. For example, promoting abstinence among young girls who are often not in control of the sexual experience, or who are living in poverty and have sex for the material possessions it may bring, is not the most appropriate message.
- It is obvious that women need prevention methods that they can control. We need to expand options for both women and men and make sure that all those options are not male controlled or initiated.

In the short term, the female condom provides a solution to the lack of . Although the female condom was introduced in the mid 90's it is still in pilot phases and is not widely available. In 2002 the South African government distributed 220 million male condoms and only 1 million female condoms. There is little or no activism pushing for greater access for female condoms.

The progress of another women controlled option, Microbicides, has been hampered by lack of commitment to research globally. A microbicide is a substance that is inserted in the vagina or rectum that will substantially reduce the transmission of STI's including HIV. Microbicides have the potential to be a fully controlled female barrier method, which would reduce women's vulnerability to HIV

An important starting point with all groups and communities we want to engage in the microbicide agenda is that of truly informed participation, discussion and debate – this demands a high level of transparency, ensuring ongoing access to information and deliberate efforts to seek out and listen to the voices of women. Microbicides will provide part of the medium term solution.

- Challenge and change cultural norms and expectations that increase women's vulnerability and are not adequately dealt with. Maldla Sakutiwa from ZARAN notes the following ways in which culture contributes to abuse of women.
 - Women are often unable to refuse their partner sex
 - Polygamy for men is accepted
 - Enhancement of male pleasure through dry sex increases women's vulnerability and takes away from her sexual pleasure
 - Violence against women is seen as an expression of masculinity and an acceptable form of disciplining woman and girls
 - Virginity testing
 - Culture of silence about sex and sexuality²

² VSO 2003

- Promote a sexual rights framework. Hlatshwayo and Klugman (2001) suggest a sexual rights framework which embodies the following rights for men and women:
 - To have control over one's own body
 - To have sex when, with whom and how one wants and not be forced to have sex
 - To make decisions about their own sexuality
 - To have sexual enjoyment
 - To protect themselves from the risk of the consequences of sex, such as pregnancy, sexually transmitted infections and HIV
 - To have access to non-judgemental, responsive services which help deal with sexual health concerns

Let us now address the critical challenges facing us in more detail.

CRITICAL CHALLENGES

This section is based on the experiences of the Gender AIDS Forum over the last 5 years. It reflects our learnings: we began with a technical approach to addressing gender [focusing on gender analysis and planning, and gender mainstreaming] to where we are now with power as our starting point.

Whilst the section does not cover our previous approach and why we decided to change it is useful to briefly highlight this before we focus on the challenges. The dominant approach to addressing gender is through gender mainstreaming using tools such as gender analysis and planning to ensure that gender is integrated into policy and programme. GAF, adapting this approach to fit the HIV and AIDS context trained people in NGO's and CBO's "how to do" gender mainstreaming. We were, however, disappointed in the results after the workshop and realised that we were not really equipping people with skills to address gender in a meaningful way in their organisations.

We believe that gender mainstreaming is NOT the right place to start a programme that will tackle gender oppression. Based on our experience we feel that:

- "Gender" must be carefully defined to have at the core unequal power relations between men and women
- our understanding of gender must firstly focus on our PERSONAL experiences of being oppressed as women, or in the case of men to acknowledge that the privileged position of men enables men to oppress women
- our personal experiences are shared by many women and must be seen as political issues, especially to deal with the gender oppression women experience in their relationships, in the family and in the household
- technical approaches are useful but need to be developed with the people who are going to use them. Technical tools on their own cannot address the realities and complexities of women's lives.

Technical approaches are also unlikely to lead to the transformation of society but instead provide a mechanism to highlight gender issues,

This section will focus on three critical challenges that we have identified. These are:

The need to place women at the centre of a gendered response. Within this how do we ensure that we address the realities of women's lives and increase meaningful participation – especially of women on the margins

What does power mean – is all power bad? How can we re-invent power?

How do we shift from gender awareness and gender sensitivity to empowerment and transformation?

We do not necessarily have all the answers to these questions, but pose them as food for thought.

Critical challenge ONE

Putting women back into gender:

How we want “women at the centre” – but how we do not want to further marginalise men on the margins

Globally, people have come full circle in understanding of how gender should best be addressed. Initially, the focus within development was firmly on men – and their realities. In opposition to this the Women In Development approach was popularized where women's realities were central, however it was felt that this was insufficient given that men and women existed along side each other and that men were oppressed in some contexts – especially men on the margins. So the focus shifted to Gender and Development – looking at men and women's realities. Similar trends are apparent in the response to HIV and AIDS but now more and more organizations are now looking at focusing on men as sites of power: a gendered approach often means that men are the main focus and women are ignored.

GAF believe that it is essential to still keep the focus on women and girls as the most vulnerable and oppressed, and that this needs to be done within a framework of addressing the power relations between man and women. Focusing on men alone confirms their position in society as the more powerful partner – and states that without men's involvement in prevention efforts women will never be in a position to protect themselves. This is disempowering to women.

Defining gender.

The starting point should be our understanding of gender. Common to most definitions is a focus on gender as socially constructed roles and responsibilities that are assigned to men and women. Thus the focus is on the difference between men and women – with men being more valued by society than women. However, this only reflects half of the definition. If we only focus on the difference we are missing out on the reason **why** the difference is allowed to continue and how it is that men are more valued. Therefore, a more comprehensive definition or interpretation of gender sees

as central an understanding of the unequal power relationships between men and women. The power imbalance ensures that men are seen as better than women, men have access to and control most of the resources, men are in decision making and leadership positions and so on.

If we look at this extended definition of gender it is clear why we want to focus on women but not exclude men. **Women are in the center because they are still oppressed, still more vulnerable and still lack access and control over resources and importantly in the HIV context, over their own bodies.**

One critical issue is the importance of addressing women's lived realities. That is looking at women's daily lives – the difficulties, struggles, problems and making sure that these inform what it is that we do. For example, if we look at all the things one woman does in the household, we can see that she has very little time to do anything else and yet she is expected to take on the huge burden of care with little or no support from the state or even from the men around. Julian May talks about the “time poverty” of women – the reality is that women already have heavy burdens and we need to be mindful that we do not add on any more.

Part of the problem is that we do not know the realities of people's lives, or if we do these do not inform programmes and policy. We also need to think about the different identities of women and how this affects their realities.

What is our picture of mother – “married” or in stable relationship – don't think of young women – teenage girl who had to leave school in grade 7 because she was pregnant.

HIV and AIDS prevention and care – one message fits all – most of the approaches to HIV based on exclusion – either make groups invisible such as people who are differently abled, bisexual women and men, trafficked women, refugees, lesbian women or focus on “high risk groups” to blame – sex workers, migrant workers, prisoners, truck drivers

Not acknowledging people makes them more vulnerable

In Campbell

I have been a sex worker all my life and have never talked about it. Today I am going to talk about it. It is time we stopped hiding this job of ours or AIDS will kill us all.

Seidle

What is missing .. are the multiple experiences and the representations of women and children with HIV and AIDS, the knowledge of how HIV and AIDS impacts on the lives of young mothers, their families and communities. This missing knowledge is knowledge from below. This knowledge does not have the same status as medical knowledge.

SAYC

Government will decide on a programme for young people, but the youth are not consulted. The prevention messages and pamphlets that are being used do not include the youths understanding or contributions

As noted, one of the critical goals identified by GAF is to put women at the centre. This does not mean that men are not important, or are not vulnerable, or not affected by HIV and AIDS. It means that for too long, and in too many areas, women have been in the margins, with little focus on critical issues such as

- ★ Developing women controlled prevention methods
- ★ Focusing on women rather than issues for mothers and seeing the prevention of mother to child transmission as treatment for women instead of prevention of infant infection
- ★ Treatment issues for women

Women have many realities

Vulnerability is not a fixed concept – varies over time, over place

Women experience and have access to different power at different times

Let us then understand the second challenge: what is power.

POWER

Drawing on feminist theory Allen [1999] outlines three types of power – domination, resistance and solidarity that define power both as a problem as well as a solution.

This includes re-looking at the power that individuals and organisations can retain, despite of domination. No one is completely powerless. Our power may show itself in a specific way through resistance as well as through the collective power of a group working together in solidarity. Power is thus central to understanding and analysing the problem as well as providing a solution to redefine society. Concepts of power include power as resource, as domination and as empowerment.

Kabeer's analysis of power [based on the work of Lukes] defines four types of power which include: power over, power to, power within and power with³.

- **Power over**
Power over is mostly oppressive, divisive and destructive. It is the power of an individual or group to get another person or group to do something against their will. Power over is enforced through violence or fear or social rules. Power over can also be self-reinforced through fears or rules we have learned to impose on ourselves. Rape and other forms of domestic violence is a good example of this. Power over is about "control, not only over human bodies and physical and financial resources but over the ideology which sets rules and ideas⁴
- **Power to** involves resistance and empowerment – the capacity of an individual or group to act in spite of or in response to the power wielded over her by others, and to make changes⁵

³ Kabeer

⁴ Batilwala

⁵ Allen 1999

- **Power from within** is power that is self-generated. It is the recognition that one is not helpless, and not the source of all ones own problems.
- **Power with** is the capacity to achieve with others what one could not achieve alone – working in solidarity gives us greater power.

Empowerment is the capacity of women to increase their own self-reliance and internal strength. This is identified as the right to determine choices in life and to influence the direction of change through the ability to gain control over material and non-material resources⁶. Empowerment, in its most literal sense refers to people taking control over their own lives, gaining the ability to do things, to change and define their own agendas⁷. Empowerment also involves creating an enabling environment in which women reconstruct and reinvent themselves. This involves rising above the barriers, confronting and overcoming fear and doing things never thought possible.

However, Rowlands notes that empowerment is difficult to define. Such difficulties arise because the root concept, power is disputed. Most frameworks for understanding power are gender neutral and do not analyse how power is distributed within society – including the power dynamics of race, class, gender and other oppressions⁸.

It is possible to address different types of power within an empowerment framework:

- **Power over.**
Empowerment involves bringing people into the decision making process. The emphasis is on participation in politics, formal decision making, economics, ability to obtain income and increasing access and control over resources.

Example

This is a well used strategy to bring the enemy into the fold so to speak – for example having women in parliament, or having NGO's sit on the South African National AIDS Committee neutralizes the activism and demands for more action.

- **Power within:**
Empowerment processes by which people become aware of their own interests, as well as processes that lead people to perceive themselves as able to and entitled to make decisions.

Example

Getting women to believe in and articulate their sexual rights

- **Power to**
Extending the power within to move from the consciousness to action in the form of resistance, empowerment

⁶ Moser 1993

⁷ Young

⁸ Rowlands

Shift from empowerment to transformation

Women are facing a crisis that requires urgent attention. The response to HIV and AIDS must be two-fold: a short-term strategy that needs to, as much as possible, reduce the spread of HIV amongst women and lessen the impact of HIV and AIDS on women. However the long term goal must be to challenge the complexities and inequalities of power relations between men and women in society leading to the transformation of society
Vicci Tallis 1998:13

The goal is to begin changing the social environment that surrounds issues of HIV infection and gender violence.
Betsi Pendry 1998:

The gendered nature of the response to HIV and AIDS can be plotted along a continuum ranging from promoting gender stereotypes through to the eradication of gender inequality through the transformation of society. The range of responses from a gendered perspective can include:

- ❖ Gender blind
- ❖ Gender neutral
- ❖ Gender sensitive
- ❖ Gender empowerment
- ❖ Gender transformation

Responses to HIV and AIDS may be positioned at any point along this continuum. The closer the response or particular intervention is to gender transformation the more fundamental the change that will emerge. It is clear that responses to HIV and AIDS have the potential to entrench or challenge the gender status quo which exists.

Taking action

Empowerment requires genuine participation. This refers to the 'intent to hand over power to interpret, analyse and come up with solutions' (Akerkar, 2001:p2). Participation can be seen as a means to an end, that is, lead to more efficient development. However, participation that is empowering is an end in itself. The people most affected by any development issue must be part of the process of defining the problem and finding solutions.

Also need to address voices of the vulnerable in setting the agenda

Transformation

Why is transformation so crucial for HIV/AIDS? The HIV/AIDS epidemics clearly flourish in the context of power dynamics that oppress women and add to their vulnerability. The challenge is to change or transform unequal power between men and women to create a context where women have equal power and both women and men are less vulnerable. Calls for the transformation of society have spanned generations, and whilst gains have been made, progress has been slow. The imperatives of the HIV/AIDS

epidemic may provide the catalyst that is needed to recognise, confront and address the inequality of women.

Young believes that empowerment involves “the radical alteration of the processes and structures which reproduce women’s subordinate position as a gender”⁹. This view of empowerment implies collective, not individual empowerment. Steps include:

- building a positive self image and self confidence
- developing the ability to think critically
- building up group cohesion
- fostering decision making and action

Empowerment means individual change and collective action. This includes enabling women to collectively take control of their lives, to organise and help each other, to make demand on the state for support and on society for change. The collective empowerment of women leads to a focus on the needs and vision of women¹⁰.

⁹ Young 1997:372

¹⁰ Ibid