



Inter-American Commission of Women



Organization of  
American States

# Ethical considerations for an integral response to human rights, HIV and violence against women in Central America







Inter-American Commission of Women (CIM)  
Organization of American States

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to human rights, HIV and violence against women  
in Central America**

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*Ethical considerations for an integral response to human rights, HIV and violence against women in Central America*

Authors: MariJo Vázquez and Fiona Hale, Salamander Trust Associates ([www.salamandertrust.net](http://www.salamandertrust.net))  
Project Coordinator: Diny's Luciano Ferdinand, Development Connections

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**Comisión Interamericana de Mujeres (CIM)**

1889 F Street NW, Washington, DC, 20006, United States  
Tel: 1-202-458-6084, Fax: 1-202-458-6094  
Email: [cim@oas.org](mailto:cim@oas.org)  
Web: <http://www.oas.org/cim>

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# Acronyms

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<b>CIM</b>	Inter-American Commission of Women
<b>ICW</b>	International Community of Women living with HIV/AIDS
<b>OAS</b>	Organization of American States
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>SRH</b>	Sexual and reproductive health
<b>VAW</b>	Violence against women
<b>HIV</b>	Human Immunodeficiency Virus



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# 1. Introduction

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How can programmes and policies respond ethically to the priorities of women and girls who are living with HIV and/or experiencing gender-based violence in Central America? What are the key ethical considerations to be taken into account in designing and implementing programmes and policies across the range of sectors which protect women and girls against violence and the negative impacts of HIV, by addressing gender inequalities and upholding human rights?

These are some of the key questions which are explored in the project “Human rights, HIV and violence against women in Central America: Integrated Responses”, which takes place in four countries in Central America, and which is led by the Inter-American Commission of Women of the Organization of American States (CIM/OAS). The goal of the project is to contribute to national and regional efforts to reduce the prevalence of HIV and violence against women (VAW) through the development of a model of integrated policies and programmes addressing both epidemics.

This technical document presents ethical considerations for an integrated approach to policies and programmes on HIV and VAW from the perspective of human rights in Central America, incorporating the following aspects:

- a. Current situation and sectoral challenges (work, health, justice, education, women’s affairs mechanisms, bodies responsible for

the integrated risk management of disasters/emergencies, and others of relevance to Central America) for programmes and policies which integrate HIV and VAW and which are based on justice, equality, gender equity and human rights.

- b.** The importance of ethical approaches to ensure that programmes and policies are ethically acceptable, fair and of benefit to women – in all their multiple identities – within sectoral systems, communities and families.
- c.** Ethical considerations by sector (work, health, justice, education, women's affairs mechanisms, bodies responsible for the integrated risk management of disasters/emergencies, and others of relevance to Central America) in key areas for the promotion of good practice:
  - Services
  - Prevention of both HIV and VAW taking into account structural and intermediary factors and consequences of both HIV and VAW
  - Social protection
  - Research, including surveillance
  - Human resource training
  - Monitoring and evaluation
  - Development of medicines, products and vaccines
- d.** Ethical considerations for the planning and implementation of policies and programmes which integrate HIV and VAW.
  - How to implement integrated policies and programmes
  - Role of people living with HIV and of communities
  - Strengthening of the sectors involved
  - Inter-sectoral coordination
  - Sustainability

The document does not claim to be the result of extensive academic research, nor does it provide a complete ethical framework. It draws on the many ethical guidelines which already exist concerning HIV and VAW respectively. It attempts to suggest ethical considerations for sectors beyond health, which traditionally have had less focus on HIV and/or violence against women, but where efforts to integrate violence against women and HIV may be particularly relevant.

Detailed discussion of each sector is beyond the scope of this document. However, the authors draw on their experiences across sectors to explore some ethical considerations and principles which illuminate these. They bring the knowledge they have gained through their engagement with women, HIV and violence, in work with communities, and their gender perspective.

The intention is that by providing a guide to ethical thinking, multi-sectoral partnerships will be able to find common ground for ethical decision-making built on the meaningful involvement of those at the intersections of violence against women and HIV – particularly women living with HIV and women with experience of violence.

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1 In other papers (such as Hale and Vázquez, 2011) the authors caution against the indiscriminate use of acronyms such as PLHIV, WLHIV, IDU, and argue that using acronyms to refer to people could constitute a specific form of cultural violence. The acronym VAW describes a phenomenon rather than a person, and therefore is perhaps less problematic. For this reason, and for ease of reading, 'VAW' will be used in this document.





## 2. Current situation and sectoral challenges in relation to the integration of HIV and VAW in policies and programmes

'All the women living with HIV in my organization have been subjected to various forms of violence before and after diagnosis, from sexual violence, psychological, economic to institutional violence. The most important lesson for us is that we are able to talk about this issue and from identification [of it], support each other and make joint decisions to seek help and improve our quality of life.'

(Latin America) (Athena Network and the Global Coalition on Women and AIDS, 2011<sup>a</sup>, p. 4)

### Context

Violence against women is a worldwide problem of significant scale (WHO, 2005). For many women around the world, partner violence is a feature of daily life, although it is rarely discussed, even with friends and family (Garcia Moreno, 2006). Violence is associated with immediate and long term health outcomes including injuries, physical and mental health problems, substance abuse, and death (WHO, 2011). Violence against women is intimately linked with HIV. Women who have experienced violence are more likely to acquire HIV, and women living with HIV are highly likely to experience violence (Dunkle et al, 2004; Human Rights Watch, 2007; Maman et al, 2002; Murray et al, 2006; Picasso, 2008<sup>a</sup> and b; Watts, 2009; World Health Organisation and London School of Hygiene and Tropical Medicine, 2010). Gender inequalities and other social markers, such as ethnicity, class, age, disability, and HIV status, intersect with structural processes to place women in positions of vulnerability to violence in many different settings: in the home, within the larger family setting, in the community, the workplace, in health, education and other service settings (Luciano, 2009; Sandelowski et al, 2009). Women also experience structural and cultural violence (Farmer et al, 2006) in the form of laws, policies, practices, and aspects of culture which undermine their rights and expose them to repression, marginalisation, exploitation and further violence.



To reflect the diversity of women's experiences of violence, this report uses a broad definition of violence encompassing direct, structural and cultural violence. A specific definition of violence against women with HIV is also used, to include 'any act, structure or process in which power is used in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV' (Hale and Vázquez, 2011, p. 13). This definition is based on our understanding of the impact HIV has on women, and our commitment to the rights of women, including women living with HIV.

As awareness of violence against women has increased, a number of different, but overlapping, approaches have been developed to understand, describe and systematise knowledge related to violence against women. These approaches include:

- The gender perspective
- The human rights perspective
- The criminal justice perspective
- The public health approach (WHO and the London School of Hygiene and Tropical Medicine, 2010, p. 6)
- The citizen security approach (Whitzman, 2008)

A decade ago, international organisations working on HIV and women's human rights identified links between the two epidemics. A number of international agreements – including the Declaration of Commitment on HIV/AIDS (UN, 2001) and the San Salvador Declaration on Gender, HIV and Violence against Women (CIM/OAS, 2007) – acknowledged that eliminating violence against women contributes to reducing the spread of HIV.

However, translating this commitment into practice raises practical dilemmas such as scarcity of resources or the lack of specific training among those working on the ground. It also raises ethical dilemmas in relation to concepts such as justice, respect for autonomy and beneficence. These impact directly on the distribution of existing resources, on the extent to which training is valued and carried out, and so on. The integration of HIV and VAW is firmly based on ethical



considerations founded on equity and social justice, utility, efficacy and efficiency (Luciano, 2007). It is important not because someone has taken an arbitrary decision that integration is good, or because of the demands of women or professionals working in the sector, but because not to do so would undermine personal and professional ethics and would lead to practices which ultimately are damaging to those affected and, consequently, to society itself.

This section will address the current situation and sectoral challenges (work, health, justice, education, women's affairs mechanisms, bodies responsible for the integrated risk management of disasters/emergencies, and others relevant to Central America) for the integration of programmes and policies on HIV and VAW, from the perspectives of justice, equality, gender equity and human rights.

Both VAW and HIV have a huge impact on women's access to work, health, justice, education and services generally. In any sector, those policies and programmes which do not take into account the needs of women may exacerbate the effects of violence and HIV (Hale y Vázquez, 2011). Even when they are well-intentioned, they inevitably expose women to greater levels of violence, or pose problems for HIV prevention, care, treatment and support for women.

With the global rise in HIV prevalence among women, and growing awareness of the worldwide problem of violence against women, there is increasing support for the idea that the development of ethical policies and programmes on HIV on the one hand, and on violence against women on the other, must find ethical approaches to crucial issues such as women's empowerment and rights, equality, and gender equity, as well as the role of power dynamics in any initiative to address the structural factors common to both violence against women and HIV. It is equally necessary to increase the understanding of professionals that violence against women is something which intersects with HIV throughout the life cycle (Picasso, 2008a y 2008b), and that responses to violence must include and be adapted to the different life cycles of men and women.

Whole-system and whole-society approaches are needed: responses which see men simply as perpetrators of violence against women miss the opportunity to tackle vital underlying structural and cultural causes.

'I am 17. I have a 3 month old baby. I acquired HIV/AIDS from my mother. She had the virus because she was raped by her step-father. He raped her, my aunts, and he had sexual relations with my grandmother, his wife. They all got HIV. My mum could leave, so she did. She left home and got together with my dad when she was 13 or 14. She passed the virus on to my dad without knowing it... My little sister is 14 and luckily her health is good, like mine is, but her situation is different to mine – she does not have the virus. .. My mum died when she was 19 and I was 3, and my dad died at 33 when I was 12... When my mum and dad had both died, I went to live with my grandmother. At first she treated us well, but as my body started to develop when I was 10, my step-grandfather raped me and my sister. We told my grandmother, but she didn't want to listen. I did not really have a childhood or adolescence.'

Morena, 19, Panamá (ICW Latina, 2007, pp. 69-70)

In Central America there is a good basis for integration. In all four participating countries and across all sectors, there is enthusiasm for the project of integration of HIV and VAW (CIM, 2010<sup>a-h</sup>). Furthermore, the project countries have taken some initial steps; El Salvador and Honduras (along with Nicaragua) were the only three countries in a nine-country study to have developed HIV prevention programmes focused on the links between gender violence and HIV (Kendall et al, 2011).

A global problem is the fact that research into the links between violence and HIV has been fragmented. In Central America, there is also a lack of systematic data collection, although there have been some descriptive studies which document some of the ways in which HIV and VAW are linked (PAHO, 2006, cited in CIM, 2010c, p. 44; PAHO, 2008, cited in CIM, 2010<sup>a</sup>, p. 53). However, there is a high degree of acknowledgement of the links between the two in the region, which is clearly expressed in documents as significant as the Convention of Belem do Pará (OAS, 1994) and the Declaration of San Salvador (CIM, 2007).

However, despite these declarations of understanding and intent with regard to integration of HIV and VAW, situation analyses and mappings

of social actors conducted in El Salvador, Guatemala, Honduras and Panama under the CIM project detail a number of sectoral challenges. We will not reproduce these here, but will briefly summarise some of the key issues<sup>2</sup>:

- Challenges exist across the range of sectors. These vary from one country to another.
- Women's affairs mechanisms are seriously under-funded.
- There is little understanding of the links between women's empowerment, livelihood opportunities and violence.
- There are inconsistencies between employment legislation and legislation to protect people living with HIV.
- The sexual and reproductive rights of women generally, and HIV positive women particularly, are not respected.

The justice system is not well equipped to deal with partner violence, or violence against women in the context of sex work or drug use. Problems arise with the criminalisation of sex work and drug use, and the implied criminalisation of HIV (as reflected in the obligation for sex workers to be tested for HIV, as well as in laws which impose maximum penalties for those who 'infect' other people, etc). While the project countries have ratified the main international conventions on women's rights, access to those rights is often limited, with an example being the fact that abortion is illegal in the four project countries.

Across all sectors, there is a lack of training for staff on how violence against women and HIV intersect and impact on women's lives. Structural violence is a major issue for women, and is manifested in women's lack of economic power, the discrimination and abuse women experience in employment settings, and the greater poverty indicators among women. In rural areas particularly, women lack access to education, health services, employment opportunities, and recourse to justice. Schools and educational institutions do not provide sex education based on

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2 The complete reports are available in Spanish on the CIM website: <http://www.oas.org/cim>



respectful and gender-equitable relationships. Women's organisations are underfunded, and civil society organisations working on violence against women struggle for resources and as a result are often short-lived. Risk management strategies in emergency situations often fail to address HIV and VAW, despite the fact that the countries of Central America face constant disasters (hurricanes, earthquakes, floods etc).

Despite these challenges, which are similar to those seen all over the world, there are reasons for optimism. There is a strong history in Central America of participatory approaches, community work, and work on human rights, although these have not been applied consistently to work on HIV or violence against women. A number of active civil society groups in the region focus on promoting gender equality, and already have some established links to policy makers and programme implementers. While there is little expertise generally on integration of HIV and VAW, there is considerable expertise on the two issues separately, including within government agencies and civil society organisations.

Much of the expertise and leadership on HIV and VAW in government institutions is found within the health sector. In the four countries, the Ministry of Health and national coordinating bodies for HIV and violence against women are key actors for integration, although there is strong positive multi-sectoral involvement including ministries of justice, education and economy, among others, demonstrating their understanding of the need for a broad and integrated approach if both issues are to be addressed in the best possible manner.

In terms of non governmental agencies, a number of civil society organisations have specific expertise in the integration of the response to violence against women and HIV, and focus on the involvement of women living with HIV as central to the response (in El Salvador: ICW El Salvador, CEMUJER, Las Dignas, Las Mélicas, among others; in Honduras: CDM, CEM-H, Foro Nacional de SIDA, Pastoral Social de Cáritas, Calidad de Vida, CODEMUH, ASONAPVSI DAH, CONADEH, CIPRODEH; in Guatemala, Gente Positiva, Mujeres Positivas en Acción;

in Panamá, ICW Panamá, Asociación Viviendo Positivamente and Coordinación Nacional de Mujeres Indígenas de Panamá). Many of the women's organisations and the networks of women living with HIV are working actively to better understand and unpick the links between HIV and VAW, such as through the Guatemalan Positive Women In Action campaign "Women Won't Wait: Let's End Violence Against Women NOW" ("Las Mujeres NO Esperamos, Acabemos la Violencia Contra las Mujeres y el VIH YA!"). Unfortunately, these organisations are often seriously underfunded, which affects their impact, despite them being among the most important actors for integration of HIV and VAW.

The next section explores the importance of ethics to ensure that programmes and policies are ethically acceptable, fair, and beneficial to women – in all their multiple and overlapping identities – within the various sectoral systems, communities and families.





### 3.

## Importance of taking ethical considerations into account

“Most of the HIV prevention programs [focus on reducing] risk factors that increase the possibility of getting HIV (number of sexual partners, use of condoms, etc). Almost no HIV prevention or care program is directed to reduce the vulnerability conditions in which women acquire HIV (for example poverty, violence, gender roles, lack of education, lack of leadership).”

(Latin America) (Athena Network y Global Coalition on Women and AIDS, 2011<sup>a</sup>, p. 4)



Foto: <http://www.flickr.com/photos/unhcr/3341487870/sizes/l/in/photostream/>

Before addressing the specific ethical considerations for the integration of HIV and VAW in Central America (section 4), this section explores the key concepts and principles involved in ethical decision-making based on human rights, equality and gender equity.

## What is ethics?

Ethics is defined as ‘moral principles that govern a person’s behaviour or the conducting of an activity’ (Oxford English Dictionary). The Markkula Centre for Applied Ethics provides a useful list of what ethics is NOT:

- Ethics is not the same as feelings.
- Ethics is not religion.
- Ethics is not following the law.
- Ethics is not following culturally accepted norms.
- Ethics is not science (Markkula Centre for Applied Ethics, 2009).

Ethics is certainly not about unquestioningly following cultural norms. However, it is important to acknowledge the ethical tension between respect for universal ethical principles on the one hand, and the importance of culturally appropriate responses on the other. Ethical analysis must reflect both internationally accepted norms and locally relevant cultural values (WHO, 2009).

## Ethical principles

Different ethical traditions emphasise different principles and values depending on the focus of their actions. Many disciplines have developed their own ethical codes, and professionals from different background and disciplines may take different approaches to ethical problems. The principle of justice has been fundamental to human rights approaches, particularly the idea of distributive justice in which the needs of those



people and groups that are most vulnerable and socially disadvantaged receive particular attention (Stanford, 2007). However, the three fundamental ethical principles of respect for autonomy, beneficence and justice (Beauchamp y Childress, 2001) are common to ethical decision-making across a wide range of environments:

- **Respect for autonomy** entails respecting people's ability to think, decide and act for themselves, respecting the decisions people make about their own lives, providing the means for them to do so, and protecting people who are not able to make decisions for themselves. It also imposes an obligation to treat people with respect by maintaining confidences and keeping promises.
- **Beneficence** imposes a positive obligation to act in the best interests of the people who will be affected. The related principle of non-maleficence imposes the obligation to avoid any harm occurring to those affected. Beneficence and non-maleficence form part of a continuum, and have the good of people at the centre. For reasons of simplicity, this document uses beneficence with the understanding that the analysis needed for the practice of beneficence involves consideration of non-maleficence as its counterpart, particularly when complete beneficence for all involved is not a possibility. The aim is that any action should focus on doing as much good and as little harm as possible.
- **Justice** requires that people be treated fairly. It is often understood to require that benefits and burdens be distributed fairly within society.

A key difference which has been the subject of much debate in recent years is the difference between the ethics of care and the ethics of justice (which refers to an impartial concept of justice, compared to the distributive justice referred to above).



'The ethics of justice constitutes an ethical perspective in terms of which ethical decisions are made on the basis of universal principles and rules, and in an impartial and verifiable manner with a view to ensuring the fair and equitable treatment of all people. The ethics of care, on the other hand, constitutes an ethical approach in terms of which involvement, harmonious relations and the needs of others play an important part in ethical decision-making in each ethical situation.'

(Botes, 2000)

Feminist approaches to ethics highlight these relational or 'ethics of care' principles, and prioritise gender equality, participation, solidarity and empathy (Gilligan, 1982; Whitford, 1991; Slote, 2007). Public health codes of ethics may emphasise social justice, an ethics of care for the most vulnerable (Gostin and Powers, 2006), and human rights (Gruskin, Bochego and Ferguson, 2010). Community development approaches are often based on social justice values, such as the distribution of resources so that everyone can live a decent life; equal human rights for all human beings in all their diversity; and all people to be represented and able to advocate on their own behalf (Klugman, 2010). HIV activists have long called for ethical responses to HIV to include GIPA (the Greater Involvement of People living with HIV), now often referred to as MIPA (the meaningful involvement of people living with HIV), or MIWA (the meaningful involvement of women living with HIV), promoted by the International Community of Women living with HIV/AIDS (ICW) the Global Network of People living with HIV (GNP+), the NGO Code of Good Practice, and others. Researchers working on violence against women also follow an 'ethics of care' approach, detailing particular principles to be taken into account to ensure that research and responses to the issue are ethical, and do not cause further harm, whether by action or omission, to either the women participating in research, or the researchers (Ellsberg and Heise, 2005).

To ensure that any decision-making in research, in policy development and in service delivery does good rather than harm, and is respectful and fair, it is important to have a full understanding of the cultural context and a decision-making process which is ethical. Good decision-making depends on getting the balance between universal ethical principles and culturally

relevant actions within each context. It also requires ethical conduct in any intervention carried out at community level. Rabinowitz (2011) suggests that this is important for the following reasons:

- It improves programme efficacy
- It increases community respect
- It increases credibility and moral leadership
- To conform to legal and professional codes of ethics governing some of the professions involved (social work, law, etc).

Ethical decision-making processes are key to public trust in decision-makers, and ethical principles are useful guidelines. However, ethical conduct is not merely the formal adoption of theoretical principles, but involves the art of applying these principles to professional and personal conduct. The decisions taken must be coherent with the principles adopted, and appropriate to the specific circumstances of each situation.

- The principle of cultural relevance

In relation to both HIV and VAW, it is a matter of concern that particularly western perspectives on ethics receive ongoing validation. This is reflected in approaches which are not firmly rooted in the priorities of those who are most affected and are not framed in ways which are culturally relevant.

The ethics of research into HIV prevention – for example, research into microbicide development – have challenged the application of universal ethical principles when this is not done with cultural relevance in mind, particularly with regard to the question of standards of care (Bass, 2003).

The principle of cultural relevance is also related to the question of expertise. The lack of recognition and acknowledgement of so-called ‘lay’ expertise is an ethical issue, particularly when the dominance of particular discourses (such as biomedical or epidemiological scientific discourses) negates the ‘expertise by experience’ of those most affected by HIV and violence against women, and relegates it to the category of

'anecdote' rather than 'evidence'. The fact that rich donors and donor organizations, usually based outside the cultural context in question, have the power to set priorities is also an ethical problem.

- The principle of complexity

Una de las primeras realidades que perciben las y los profesionales al introducir la reflexión ética en las intervenciones en el mundo real es que, lejos de simplificar la ya de por sí compleja cualidad de las situaciones con las que se encuentran, lo que hace es sacar a la luz esa complejidad y situarles en disposición de incorporarla como otra parte más de la situación

'When ethical reflection is used in the real world, professionals soon realise that, far from simplifying the already complex nature of the situations they find themselves in, it rather serves to illuminate this complexity, making them more able to incorporate that complexity as part of the situation.

'The principle of complexity does not deny or contradict the fundamental criteria necessary to resolve the most complex cases. It is not a case of justifying a certain behaviour, or thinking that there are no decisive solutions, but rather a case of responding to the specific situation. Anyone who thinks that there can not be values, norms and laws which can be applied to complex cases misunderstands this principle'  
(García de Alba, 1999, pp. 182-185).

Work with women on HIV and VAW brings with it significant levels of complexity, given that it incorporates medical care, justice, work, community health, social work, community action and social change.

Furthermore, numerous concurrent factors intersect to define distinct needs and vulnerabilities for different groups of women. Understanding inter-sectionality, or the interplay between social determinants of HIV and social determinants of violence against women, is crucial to an ethical response. Factors such as ethnicity, age, job status, income, class, sexuality, partnership/civil status, whether or not they have children, legal



status, immigration status, language abilities, and other factors overlap and interweave to create a pattern of vulnerabilities and strengths which change for each woman in the course of her life, and from one woman to the next. Some women are particularly vulnerable: for example, women migrants, indigenous women, women who do not speak the dominant language. The recent Virtual Consultation, carried out by the Athena Network and the Global Coalition on Women and AIDS (2011b), gathered these and other factors and identities as expressed by the women participating in the consultation in an image which graphically illustrates this diversity (see page 35 of this document).

Any work which ignores the realities of the situation it intends to address is unlikely to be successful. At the same time, it is important that the complexities of the situation do not contribute to a dilution of the overall goal of the intervention.

- The concept of moral standing

The concept of moral standing is an important aspect of ethics in relation to violence against women and HIV. A person is considered to have moral standing if we believe that *'it makes a difference, morally, how that individual is treated, apart from the effects it has on others. That is, an individual has moral standing for us if, when making moral decisions, we feel we ought to take that individual's welfare into account for the individual's own sake and not merely for our benefit or someone else's benefit'* (Andre y Velásquez 1991).

There is a history of women living with HIV not being accorded moral standing. Many initiatives treat women as 'sources' or 'vectors' of HIV, and not as people with visions, needs and rights. This can be seen for example in those interventions to prevent vertical transmission of HIV which focus exclusively on the outcome for the infant, and fail to ensure good care, treatment and support to the mother (and her partner); or in HIV prevention work which seeks only to prevent the spread of HIV to those who are HIV negative, without also promoting the health and rights of those who are

already HIV positive. The moral standing of sex workers is also frequently neglected, when sex work legislation fails to give due consideration to the health and well-being of women sex workers, or in interventions which see women sex workers primarily as a public health problem or a possible source of HIV. Similarly, attitudes to violence against women frequently show a lack of regard for the moral standing of the women experiencing violence, because of entrenched gender discrimination, inequality and judgemental attitudes towards women in particular circumstances. In the case of integration of HIV and violence against women, what is required in place of this discrimination is what the philosopher Michèle Le Doeuff calls 'an ethics of solidarity and the obligation to assist whoever is in danger' (Le Doeuff, p. 343, cited in Whitford, 1991, p. 4).

This is linked to the notion of empathy, which is a crucial element in an ethics of care approach (Slote, 2007). Using empathy as a lens, or 'walking in the shoes of those affected' (Nadler, 2010), the key ethical principles of respect for autonomy, beneficence/non-maleficence, and justice can be applied in a way which promotes social justice, human rights and well-being of the most vulnerable. These are all key considerations with regard to violence against women and HIV (Luciano, 2007), where the focus must be on women-centred approaches which are based on the realities of women's lives in all their diversity.

- Personal commitment

Ethical decision-making depends on personal commitment, which requires each of us to take individual and institutional responsibility for the impact of our decisions on others. Personal commitment must be backed up by institutional commitment. In many cases, the institutional frameworks needed to promoting ethical decision-making are lacking. Sometimes personal decisions are based on institutional guidelines which violate human rights principles, such as in cases of HIV testing by employers without informed consent; schools refusing to accept children of HIV positive parents; or programmes to reduce peri-natal transmission of HIV that focus on the foetus to the exclusion of the mother as a person with rights.







In this case, the question is the extent of personal commitment to the rights of women and girls, with their multiple and overlapping identities, and personal responsibility of all involved for the impact of decisions on HIV and violence against women. However, this personal commitment must be matched by a commitment to debate and dialogue involving all stakeholders, including those most affected, to enable full understanding of the different viewpoints and perspectives which are vital for good ethical decision-making (Markkula Centre for Applied Ethics, 2009).

- The ethical pathway

Following an ethical pathway will always raise questions, many of which have no clear answer. The effort each person makes to answer these questions sincerely is what will make for a collective effort which is appropriate to the context of the intervention. Keeping in mind those people and elements which are central to the situation is vital for responding to the actual needs in the most appropriate and ethical manner. In the regional context, this may involve considering how to interpret ethical guidelines on confidentiality in smaller countries where 'everyone knows everyone else', or the provision of services (justice, health, social support) as an integral part of prevention of HIV and VAW, and the extent to which it is necessary to include here community justice and informal support. The answers to the questions which arise will vary from one place to another and will involve different people in each place. Starting from the right ethical principles makes it possible to find valid responses, not because there are 'right' and 'wrong' answers, but because each situation requires consideration on its own merits.







So what does this mean for the development and implementation of integration of HIV and violence against women in policy, programming and practice?

## Guide to ethical decision-making

In summary, ethical decision-making is not straightforward. It requires accepting complexity; debate and dialogue with those affected; and understanding of different viewpoints. It is particularly dependent on personal, organisational and institutional commitment.

A number of guides to ethical decision-making exist, based on different theories of ethics and different disciplinary traditions. The guide developed by the Markkula Centre for Applied Ethics may be useful as a starting point for inter-sectoral decision-making on violence against women and HIV, in that it incorporates different ethical theories as well as the idea of empathy, 'walking in the shoes of those affected', and participation of those who will be most affected by the decision.

### Who are the people most affected?

-  Women and girls living with HIV
-  Women and girls who have experienced violence
-  Women and girls who are at risk of HIV
-  Women and girls who are at risk of violence
-  Carers of women and girls affected by HIV
-  Carers of women and girls affected by violence

## Framework for ethical decision-making

### Recognize an ethical Issue:

1. Could this decision or situation be damaging to someone or to some group? Does this decision involve a choice between a good and bad alternative, or perhaps between two 'goods' or between two 'bads'?
2. Is this issue about more than what is legal or what is most efficient? If so, how?

### Obtain the facts:

3. What are the relevant facts of the case? What facts are not known? Can I learn more about the situation? Do I know enough to make a decision?
4. What individuals and groups have an important stake in the outcome? Are some concerns more important? Why?
5. What are the options for acting? Have all the relevant persons and groups been consulted? Have I identified creative options?

### Evaluate alternative actions:

6. Evaluate the options by asking the following questions:
  - Which option will produce the most good and do the least harm? (The Utilitarian Approach)
  - Which option best respects the rights of all who have a stake? (The Rights Approach)
  - Which option treats people equally or proportionately? (The Justice Approach)
  - Which option best serves the community as a whole, not just some members? (The Common Good Approach)
  - Which option leads me to act as the sort of person I want to be? (The Virtue Approach)



■ **Make a decision and test it:**

7. Considering all these approaches, which option best addresses the situation?
8. If I told someone I respect-or told a television audience-which option I have chosen, what would they say?

■ **Act and reflect on the outcome:**

9. How can my decision be implemented with the greatest care and attention to the concerns of all stakeholders?
10. How did my decision turn out and what have I learned from this specific situation?

(Markkula Centre for Applied Ethics, 2009)

The problem with this and other frameworks is that specific situations call for complex decision-making which must be based on shared values and principles and the personal commitment of those involved. Without this, it is unlikely that aspects which are crucial to the success of policies and programmes on HIV and VAW (such as meaningful participation of women with HIV and women experiencing violence) will be given their due consideration.

In addition, for integration of HIV and violence against women, careful consideration should be given to the following questions in relation to any policy, programme, service or intervention:

- a. How will it contribute to achieving the visions of those women and girls who are most affected, in all their multiple identities?
- b. How will it impact on women?
- c. How will it impact on women living with HIV?
- d. How will it impact on women experiencing violence?
- e. How will it impact on prevention of violence against women?
- f. How will it impact on prevention of HIV?

Of course, 'women' are not homogenous, and women's experiences vary according to their location, situation and identity. The issues may be different for indigenous women, women of African descent, sex workers, women who use drugs, women with children, migrant women, married women, young women, old women, heterosexual, bisexual, lesbian and transgender women, disabled women, women who are deprived of liberty. To be given the consideration they merit, and to ensure ethical decision-making, it is important to ensure that women – from their multiple and overlapping identities – are involved in the discussions, and that all decisions are based on learning from their perspectives and experiences.

On the basis of this understanding of ethics, section 4 will explore specific ethical considerations for different spheres of work.

Responses given by the women participants in the Athena Network/Global Coalition on Women and AIDS Virtual Consultation (section 5, part 1, “Our multiple identities”)

Donna Giovane donna Donna anziana Donna che convive con l'HIV Lesbica / Bisessuale / Donna che fa sesso con altre donne Donna transgender Donna eterosessuale Donna che è o è stata lavoratrice del sesso Donna che usa o ha usato droghe iniettabili Donna che ha avuto partner che usano o hanno usato droghe iniettabili Donna il cui partner convive con l'HIV Donna che si prende cura di bambini con l'HIV Donna i cui membri della sua famiglia estesa hanno l'HIV o che ha amici cari che hanno l'HIV Donna attualmente detenuta o che lo è stata in passato Donna che si prende cura degli altri Donna che fa sesso di sopravvivenza Donna senza fissa dimora Donna che vive con altre disabilità Donna che vive in una città Donna che vive in un paese Donna che vive in una zona rurale Madre Grassroots organizer Man Woman whose husband is HIV negative, and a person with disability. Director of a NGO(CHIRAG) working for PLHA in Mumbai Single Mom Woman who is a HIV/AIDS awareness educator and HIV/AIDS involvement Women's rights defender Woman working closely with sexual minority people with HIVs Woman working in HIV awareness Woman Physician treating patients with HIV/AIDS Man Woman with multiple male sexual partners Widow Indigenous woman living with HIV (now deceased) Woman working for a charity - care and support for people living in a discordant relationship Working woman Woman working for a charity for people living with HIV and their families Female Activist Researcher on HIV transmission and women's empowerment Student Single mother Sita Working mother Person who lives with a sex worker, single mother, and by the family of been HIV positive Woman imparting sex education to children and young adults Woman working with cancer patients Woman whose partner does not live with HIV Change-maker / Action Planner Woman with a disability Doctor Woman who work with global health issues Lesbian Woman Woman living alone Community organizer Woman who is a mother of a child with HIV/AIDS HIV/AIDS rights activist Volunteer Member of WHO/UNAIDS committees dealing with HIV/AIDS issues Woman OVC care program Member of a Feminist living in a remote area Woman who wants to help people living with HIV/AIDS Woman who is almost the sole bread winner in her family Woman who works to ensure access to care and treatment services for at risk women Professional woman who works for a woman health center Naive Woman Woman who is married Woman of 11 children who works for a woman health center Naive Woman Woman who is in recovery from alcoholism and drug addiction Smart, intelligent, married woman Woman working on HIV and Gender Issues Provider Widow Woman of Caribbean Ancestry Single parent who works in a city / working nationally Man Gay man Single woman Volunteer Mother of a child with HIV/AIDS Woman who is working on global woman's issues Passionate woman caring for her mother, daughter, mother: caring for my children and mother Woman of an ethnic minority who works in a mental illness Psychiatric survivor Student Woman with other chronic health problems and a discordant Marriage Man Woman with co-infection with Hep C Divorced woman who works full-time working professional A woman who believes in God Retired woman who works as a parent/sole bread winner Sister, daughter, cousin, foster parent, employee, voter, volunteer etc Woman working in rural areas though living in the city Woman running a community center with little resources and using her own resources Marraine d'un enfant africain Woman who works in a city with little resources and using her own resources Infirmiere travaillant avec PVIH Femme travaillant dans la réponse au SIDA Femme professionnelle engagée dans la promotion de la santé dans mon pays(SENLS) Chargée de l'animation et du suivi des activités de sensibilisation Première intellectuelle tout sexe confondu a avoir briser le silence sur le VIH au sein du milieu professionnel au sein du milieu national et au Nations unies. à ce jour aucun autre intellectuel n'a osé le faire. Je suis confrontée à de nombreux problèmes de santé dont le cancer Femme travaillant au sein d'une organisation internationale de lutte contre le VIH Militante pour les droits des femmes Femme travaillant dans un pays en développement Exemple de la promotion de la santé dans mon pays Sensibilisation contre les maladies transmissibles Secrétaire de la promotion de la santé Femme victime des violences familiale et conjugal Femme qui utilise des drogues de faible dose (sniff, fume...) Mujer que trabaja por los derechos de las mujeres y es activista Mujer que trabaja con hijos sin VIH Mujer que ha utilizado drogas no inyectables y vive con VIH jefa de familia viviendo con VIH y hepatitis C Mujer VIH trabajadora Laboradora que lucha por los derechos de las mujeres y las PVV Autosuficiente económicamente Madre Múltiple Mujer que trabaja voluntariamente para mujeres afectadas por el VIH Mujer violentada en hogar y trabaja en un centro de salud que atiende personas con VIH-SIDA Mujer profesional Mujer madre Mujer que trabaja en la intervención en la educación sexual de las niñas y adolescentes de atención a afectadas Lesbianas que trabaja a favor de las y los jóvenes que usan drogas Mujer profesional (Con carrera universitaria) Estudiante que trabaja en la respuesta al VIH + con hogar de niñas VIH + Toda mujer que este expuesta a situaciones vulnerables a todo lo relacionado con el VIH + ddh genero vhi sida its vd etc Madre Mujer que vive con un alcoholismo mujer viviendo con VIH + empun Terinfeksi HIV tapi belum mempunyai anak работавшая в области развития услуг для ЛДВ женщина -мать одиночка Вич инфицированный муж и младший ребенок.Инф.половым путем Женщина – бизнесвумен замужем,имеющая 2 детей Женщина-Христианка нет нижней челюсти специалист, работающий женщинами секс бизнеса женщина, живущая с ВГС состою в дискордантной паре Женщина

Source: 'Our identities' Athena and Global Coalition on Women and AIDS, 2011b.





## 4.

# Sectoral ethical considerations in key areas for the promotion of good practice

‘Sex education and sexuality issues in my country remain a taboo, leading to the high incidence of HIV in youth.’

(Latin America) (Athena Network et al, 2011a, p. 6)

‘Minority groups such as sex workers or migrants often avoid health services for fear of discrimination or judgmental treatment.’

(Caribbean) (Athena Network et al, 2011a, p. 7)

This section explores the key ethical considerations for good practice in the integration of HIV and VAW across different sectors. It uses the three fundamental ethical principles described in section 3 – respect for autonomy, beneficence and justice – to suggest key questions and considerations for each sphere of work.

It is important to bear in mind that good practice should not be focused solely on partner or family violence, though this is of course extremely important in its own right. It is pertinent in this section to re-emphasise the range of types of violence against women and the ways these intersect with HIV. The following discussion of ethical considerations by sector builds on our broad definition of violence against women as structural, cultural and direct, and the definition of violence against women living with HIV as ‘any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV’ (Hale and Vazquez, 2011, p. 13).

Many existing documents have analysed the gender dimensions of policy and programming across different sectors, and have made recommendations. The purpose of this document is not to replicate or reproduce those recommendations, but to focus on the ethics underlying them.



## 4.1 Services

Across all sectors, services have an important role in integration of HIV and violence against women. Both HIV and VAW affect all aspects of women's lives, and services must be designed to reflect this and cover from different angles all the aspects of life which may be affected. While services such as health, reproductive health, education, prison services, police services, legal services, disaster and emergency services and others may each face particular ethical issues when it comes to integrating attention to HIV and violence against women, the broader question is how to ensure that across the board, all services work with women in ways which respect their particular circumstances and are conscious of the impact of each service on other areas of their lives.

Ethical service provision for women must be designed with women at the centre. HIV services must integrate services to respond to violence against women and sexual and reproductive health (SRH) as well as sexual and reproductive rights. At the same time, VAW and SRH services must integrate HIV. Women's empowerment must be an aim of all services, including the empowerment of women living with HIV and those who have been exposed to violence. This is key to ensuring that women are able to take control of their lives and that services do not become another site of victimisation of women, but rather promote self-determination.

Particular ethical considerations within service settings may include the need to ensure confidentiality, respect for (service user) autonomy, and creation of conditions facilitating decisions around informed consent. Respect for human dignity and diversity, including cultural, ethnic, religious, and lifestyle diversity is particularly important. Service providers are not always well equipped to deal respectfully with difference, and this may leave some women excluded from services, constituting another form of violence against women.

The design of all types of services (including health, education, financial, legal, disaster and emergency and others) should ensure that they are



safe spaces for women, both as staff and as service users. If the service does not provide an internal environment for women staff which is safe and free of violence and prejudice (which is a subtle form of violence in that it constrains informed decision-making), it is unlikely to be experienced as such by other women using the service. Integration of HIV and VAW within services needs to see women not just as service users; services across all sectors need to become good employers of women, including women living with HIV, and to ensure that the workplace becomes a space which empowers women, promotes their rights, and counters all forms of violence against women staff. Good employment practice with regard to HIV and violence against women is a vital component in building ethical services which integrate HIV and VAW (Odetoyinbo, Stephens and Welbourn, 2009). This point will be further explored in sections relating to social protection and human resource training, below.

Consideration must be given to HIV and violence against women as intersecting issues to be addressed together. Referral systems between services must also address both violence against women and HIV. Services focusing on violence against women must address the needs of women living with HIV. Services focusing on HIV must address the needs of women experiencing violence. In both cases, the services provided should take into account the fact that women facing violence and women living with HIV are particularly vulnerable. Fear, stigma, and limited freedom as a result of violence may make it difficult for women to access services. Value judgements by service providers can influence the decisions of service users and make it difficult for them to access those services. For those women who do access services, the same factors may mean they find it difficult to make decisions, affecting the degree to which consent is informed. A number of studies explore this issue, and some useful resources provide further insights in this regard (see for example Ward, 2008).

Key ethical questions for services may include the following:

<p><b>Respect for autonomy</b></p>	<ul style="list-style-type: none"> <li>• How can services be set up to best ensure that they support full respect for the autonomy of women and girls in their multiple identities?</li> <li>• How should services be designed to guarantee a respectful environment in which women and girls can make their own decisions about their sexuality without fear of being judged by the professionals providing the services?</li> <li>• How should they be designed so they support women to make their own decisions about their lives, health, education, sexuality, reproductive options, livelihoods, relationships?</li> <li>• How can privacy, confidentiality and safety of women and girls be guaranteed, particularly with regard to matters relating to HIV and violence against women?</li> <li>• How can employment practice within services uphold and support the rights of women?</li> </ul>
<p><b>Beneficence</b></p>	<ul style="list-style-type: none"> <li>• How can service providers ensure that services benefit women, particularly with regard to the impact of services on HIV and violence against women?</li> <li>• How can this become part of the process of service development and evaluation, particularly for services which are not directly concerned with HIV and/or violence against women?</li> <li>• How can service providers ensure that services – including those not specifically focused on HIV and/or violence against women – do not have harmful (unintended) consequences for women with respect to HIV and/or violence?</li> </ul>
<p><b>Justice</b></p>	<ul style="list-style-type: none"> <li>• How can services ensure that all women and girls can access them?</li> <li>• How can services be set up so as best to meet the visions and needs of different groups of women and girls, including those who may traditionally have been poorly served?</li> <li>• How can services take into account the autonomy, visions and needs of women regardless of their age, socioeconomic status, ethnicity or lifestyle (for example, sex workers, women who use drugs, migrant women, heterosexual, lesbian, bisexual, and transgender women, and other groups of women)?</li> <li>• How can adequate and appropriately monitored budgets be allocated to ensure that VAW and HIV are integrated into service provision in all sectors?</li> </ul>

## 4.2 Prevention of HIV and VAW

Since violence against women and HIV are structural problems, it is vitally important that structural factors be taken into account in developing responses.

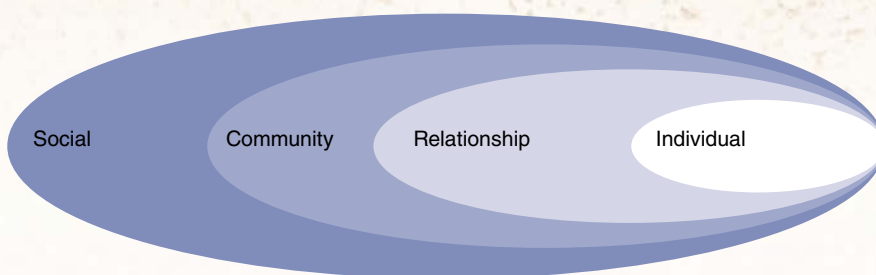
Poverty, violence and gender inequality are well known underlying causes of the disproportionate impact of HIV on women. However, these are usually given less importance than debates on individual risk factors (Watts, 2009, pp. 3-4). Structural and cultural discrimination and gender inequality are key to violence against women (Sen, Ostlin y George, 2007).

An ethical response to HIV must focus on these underlying factors and the structural issues which sustain them. The development of policies, programmes and practices related to the protection of women's rights and equality and the closing of the gender gap in education, employment, justice, access to housing, social protection, access to water and sanitation, access to health care, sexual and reproductive rights, land and inheritance rights, access to credit, etc, play a vital role in reducing violence against women and at the same time reducing their vulnerability to HIV and to HIV-related violence, stigma, and discrimination.

In other words, an ethical response requires primary, secondary and tertiary level responses to violence against women (Dahlberg and Krug, 2002) – tackling structural, intermediate and direct factors in violence against women, offering immediate responses to violence and ensuring long term care, rehabilitation and reintegration after experiences of violence. Following the ecological model of gender-based violence proposed by Heise, Ellsberg and Gottemoeller (1999), this type of integrated response to violence against women should incorporate legal, institutional and social change to address social, community, relationship and individual factors, in order to promote equality, gender equity and human rights at all levels.



## The Ecological Model



- +Norms that guarantee men's control over women's behaviour
- +Acceptance of violence as a method of resolving conflicts
- +Notion of masculinity linked to domination, honour or aggression
- +Rigid gender roles

- +Being a man
- +Witnessing spousal abuse during childhood
- +Absent or distant father
- +Suffering abuse during childhood
- +Use of alcohol

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(Heise, Ellsberg y Gottemoeller, 1999, p. 8)

In general, HIV prevention efforts have focused on specific population groups (sometimes referred to as vulnerable populations, key populations, or most at-risk populations). However, there are growing numbers of women living with HIV who do not belong to these population groups. A recent study involving Guatemala, Honduras and El Salvador as well as other Latin American countries, showed that HIV prevention efforts are not adequately focused on women (Kendall et al, 2011).

Guatemala's national HIV strategy lacks a gender perspective, and HIV prevention is only mentioned in relation to women sex workers. There is no HIV prevention provision for young women, indigenous women or women of African descent, women who use drugs, migrant women and women partners of migrant men, women partners of men who also have sex with men, or women who are deprived of liberty (in prison or psychiatric institutions). El Salvador and Honduras are two of a small number of countries in the region which mention HIV prevention for women in the general population, although this is limited to women of reproductive age

in the context of prevention of peri-natal transmission of HIV (Kendall et al, 2011, p. 16). Female condoms are not part of any national HIV strategy in the study, and HIV prevention for women beyond prevention of vertical transmission is mentioned specifically only in Honduras. This lack of distributive justice in relation to HIV prevention in the health sector, education, community, the media and other environments is an important ethical problem.

The use of ethical considerations to promote good practice requires the inclusion of HIV prevention technologies such as male and female condoms, pre and post-exposure prophylaxis and universal access to HIV treatment, care and support not only as part of an ethical response but also to avoid greater harm in the form of the violence experienced by women as a direct or indirect consequence of HIV.

<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can HIV prevention initiatives respect the autonomy of women and girls in their multiple identities, including creating safe, non-judgemental spaces where women can make informed decisions?</li> <li>• To what extent do HIV prevention initiatives such as prevention of vertical transmission, behaviour change programmes, condom promotion, HIV testing initiatives, partner notification programmes and so on, guarantee the autonomy, privacy and confidentiality of women and girls?</li> <li>• How can HIV prevention programmes – whether primary, secondary or tertiary prevention - best ensure the meaningful involvement of women and girls in their design, implementation and evaluation?</li> <li>• How can programmes to prevent violence against women respect the autonomy, confidentiality and privacy of women and girls, including programmes in schools, workplaces, public spaces, etc?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can all the consequences of HIV and VAW prevention initiatives best be understood, to ensure that such initiatives conform to the principle of beneficence and non-maleficence?</li> <li>• How can initiatives ensure that the safety of women and girls is guaranteed when engaging in prevention activities?</li> <li>• How can HIV prevention initiatives ensure they do not cause harm or increase violence against women, and how can VAW prevention initiatives ensure they do not cause harm in relation to HIV, including in the form of HIV-related stigma and discrimination against women?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• How can HIV and VAW prevention initiatives ensure they address the needs of different groups of women and girls regardless of age, socioeconomic status, ethnicity or lifestyle?</li> <li>• How can HIV and VAW programmes best address gender equity and equality?</li> <li>• How can budget allocations ensure that HIV and VAW prevention are integrated?</li> </ul>



### 4.3 Social protection

Social protection policies which promote gender equity are crucial to ethical approaches to integration of HIV and VAW. In general, women in the project countries lack economic independence and face serious gender gaps in terms of employment opportunities and livelihoods. Maternity and child care further limit their economic independence. The right to social protection is a fundamental aspect of an ethics of care which reduces women's vulnerability to violence, HIV and HIV-related violence, stigma and discrimination.

In cases where legislation exists to provide protection and recourse to justice in the event of violence against women, social protection is often the missing link. If women are to be enabled to denounce violence, social protection must be capable of providing for their basic needs when partner and family financial support is withdrawn. Similarly, HIV testing campaigns – whether voluntary testing or provider initiated testing – must be matched by social protection for women who find themselves thrown out of the family home or losing their livelihoods as a consequence of an HIV positive diagnosis. Child protection is a further component in enabling and empowering women with regard to HIV and violence against women. ICW has documented many examples of women losing custody of their children for reasons related to violence against women, or as a result (direct or indirect) of testing HIV positive (see [www.icwglobal.org](http://www.icwglobal.org)). Cost recovery strategies across the majority of systems are a serious hindrance to the protection of rights and access to services. Women have to pay for most procedures, tests, legal papers, specialist health services, treatment, and legal assistance. An integrated response to violence against women and HIV must take this into account, and ensure that social protection measures are in place to mitigate against this.

<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can social protection support the autonomy of women and girls in their multiple identities, thereby providing protection against the causes and/or consequences of violence against women and HIV?</li> <li>• How can services accessed by women seeking support be guaranteed to be safe and non-judgemental spaces which facilitate decision-making which meets women's needs?</li> <li>• How can the privacy and confidentiality of women and girls be protected and promoted through social protection?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can social protection measures be formulated to provide the most beneficence to women and girls, to ensure the best protection from violence against women and HIV, and to best support women who have experienced violence and those living with HIV?</li> <li>• How can social protection measures ensure that they do not cause unintended harm to women and girls, particularly in terms of HIV and/or violence against women?</li> <li>• How can social protection measures ensure they address the needs of different groups of women and girls, regardless of age, socioeconomic status, ethnicity or lifestyle?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• How can social protection address women's poverty derived from HIV and VAW, including providing support which covers basic needs and facilitating livelihood strategies?</li> <li>• How can social protection guarantee equality to women living with HIV and women experiencing violence?</li> <li>• How can budget allocation guarantee ethical social protection which supports women in relation to HIV and VAW?</li> </ul>

## 4.4 Research and surveillance

‘Unfortunately, researchers are finding that the ethical principles governing research in their respective fields (e.g., public health, criminal justice, psychology, social work) do not always supply them with adequate guidance to make informed ethical decisions in their work on VAW.’  
(Aronson Fontes, 2004, pp. 141-142)

This section aims to cover social research, biomedical research, and epidemiological surveillance on HIV, violence against women, and the links between the two. While each type of research, depending on its disciplinary affiliations, will be subject to its own ethical codes, here we explore some of the fundamental ethical considerations across the disciplines.

The ethics of medical research on human subjects has long been the subject of debate and regulation, with key steps being the Nuremberg Code (1947) and the Helsinki Declaration (1964, last updated in 2008). The ethics of research in relation to HIV has also been well discussed, particularly in relation to microbicides research (Bass, 2003). Scientific bodies such as the Royal Society of Canada, as well as networks of women living with HIV, have placed particular emphasis on the ethical importance of participatory research (Royal Society of Canada; ICW, 2004a).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has produced a useful guide to ethical considerations in biomedical HIV prevention research (UNAIDS, 2007), and a companion guide to Good Participatory Practice for Biomedical HIV Prevention Trials (UNAIDS, 2011a).

Key ethical considerations include:

- Acknowledgement that as a result of trial participation, women may experience violence, including family and partner violence, but also structural and cultural violence in the form of poor marriage prospects, social ostracism, job loss, denial



of property or inheritance rights, or the denial of health care (UNAIDS, 2007, p. 40).

- Sensitivity to the possibility of domestic violence resulting from partner notification in HIV prevention trials (UNAIDS, 2011a, p. 58).
- Need for trial-related counselling to include strategies to reduce domestic violence (UNAIDS, 2011a, p. 46).

The UNAIDS guidelines take an integrated approach to HIV and violence against women, acknowledging violence against women as one of the determinants of HIV and stressing the importance of research practices which 'avoid inadvertently replicating or reinforcing them in the design and conduct of biomedical HIV prevention trials' (UNAIDS, 2011a, pp. 7-8).

The ethics of social research on women and HIV has also received significant attention. Networks of people living with HIV and their allies have worked to promote participatory research practices as a way to ensure that social research is ethical, empowering, and action-oriented.

The NGO Code of Good Practice (2009) contains a 'Self-Assessment Checklist: Women, Girls and HIV' which offers a simple tool to evaluate the sensitivity of organisations in relation to work on women and HIV.

Research on violence against women also raises important ethical issues. These include questions about:

- The safety of researchers and research participants from violence arising because of the research project;
- The risks of traumatisation of both respondents and researchers as violent experiences are recounted by women involved in the project;
- The impact of work on violence as an issue in researchers' own relationships;
- The risks of under-reporting the extent of violence experienced or perpetrated; and
- The need for research efforts to be followed up in ways beneficial to

women experiencing violence, such as increased support, public information, and law and policy changes (Jewkes et al, 2000).

In terms of epidemiological surveillance, the lack of good data collation on VAW is a problem. None of the project countries has a central source of information on prevalence, with data being held separately and in a highly fragmented way by a number of institutions. The key ethical question is how to establish surveillance systems which are capable of capturing the complexity of the issues in order to obtain a real understanding of the situation, and how to use them to ensure the greatest benefit to women themselves, and to society in general.

Alongside the ethical conduct of research, there is another extremely important ethical question. The hierarchy of evidence, which prioritises 'gold-standard' scientific research, and excludes many other kinds of evidence (including research and documentation carried out by bodies such as civil society organisations and networks of women living with HIV) is an ethical issue which urges a response (Welbourn, 2010). As sociologist Ida Susser points out, 'No scientific method is the gold standard, no matter how much it is randomized and controlled, if there is no vision behind it that reflects the needs of the affected community' (Susser, 2010).

Key questions for ethical approaches to the evidence base on women, HIV and violence include:

- Who is setting the research agenda?
- Where are young women in the research agenda?
- How does the evidence base improve things for women?
- Why are issues important to women so under-researched?
- Where are the gendered discussions of research findings?
- Why are women's experiences dismissed as 'anecdote'?
- What can be done about this? (Hale, 2010, p. 7)

<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can the privacy, confidentiality and safety of women and girls be protected and promoted throughout the research and surveillance process?</li> <li>• How can research guarantee true informed consent, when the women and girls involved are likely to be vulnerable?</li> <li>• How can research be set up so as to address the power imbalances between those collecting the data and those providing it, and ensure that women are seen as co-researchers instead of research subjects?</li> <li>• How can research on women, HIV and violence be designed so that it addresses the most pressing research priorities as defined by those women and girls who are most affected?</li> <li>• How can research initiatives ensure that they are not merely extractive, but actively help research participants?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can research initiatives ensure that women and girls do not experience additional risks of violence as a result of the research?</li> <li>• How can research result in the highest benefit for women affected?</li> <li>• How can research initiatives also protect researchers from harm, in the form of violence, psychological ill-effects, or damage to their own relationships as a result of their work?</li> <li>• What is the best way to ensure that data collection and reporting is ethical, and involves and empowers the participants?</li> <li>• How can research protocols ensure that they provide for referral of affected women to appropriate services?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• How can research and surveillance ensure it addresses the priorities and needs of different groups of women and girls, regardless of age, socioeconomic status, ethnicity or lifestyle?</li> <li>• How can research results have the greatest impact in social change (not just for the women involved but for all women in the community)?</li> <li>• How to assess potential risk of research against benefits of knowledge?</li> <li>• How can budgets best be allocated to ensure that research and surveillance is carried out ethically and with the participation of women living with HIV and women experiencing violence?</li> </ul>



## 4.5 Development of medicines, products and vaccines

‘[I]n order for us to optimize the impact of new prevention technologies, we need progressive policies, laws, affirmation of rights and support from religious leaders to bring a legal and social shift in the harmful gender norms and social driver that keep women and girls vulnerable. This need is real and the time is now!’  
(Athena Network, 2011c)

The research ethics involved in the development of medicines, products and vaccines has been explored in section 4.4., above.

Some HIV-related products raise objections on the grounds of religion or ideology. The recent 2011 International AIDS Society conference in Rome saw controversy over perceived resistance to new women-initiated HIV prevention technologies. Groups of affected women at the conference took a firm stance, including releasing a press statement strongly supporting the further development and availability of such prevention tools, stating: ‘We have evidence-based research at this conference that female-initiated HIV prevention is possible in the form of topical and oral pre-exposure prophylaxis for HIV negative women and treatment initiation regardless of CD4 cell count for HIV positive women. These findings are hugely hopeful and, with sufficient commitment, can contribute to a prevention revolution. We must have commitment and leadership to acting on these data so that we can finally stop this epidemic in its tracks’ (Athena Network, 2011c).

The ethics of availability generally – of medicines, of vaccines (including HPV vaccination), and of products such as condoms, female condoms, pre- and post-exposure HIV prophylaxis – are an issue. This is not simply a question of financial resources, though that too is an ethical issue. It is also political in nature. Neither female condoms nor pap smears are mentioned in the national plans of any of the project countries, nor do they consider contraceptive use by women living with HIV (Kendall, 2011, p. 16). Stock-outs of HIV medication and specialist products needed for HIV-related diagnostics are a major problem: a recent UNAIDS report

highlights the fact that the region's achievements with regard to HIV are 'threatened by weak logistics that lead to drug stock-outs' (UNAIDS, 2011b, p. 86).

<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can policies, programmes and distribution systems related to medicines, products and vaccines support the right of women – in all their multiple identities – to autonomy?</li> <li>• How can all services and spaces related to research and provision of medicines, products and vaccines be guaranteed to be non-judgemental and respectful of the decisions women make?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can any harm to women and girls as a result of lack of availability of medicines, products and vaccines be avoided?</li> <li>• How can medicines, products and vaccines be used to ensure the best outcomes for women and girls in relation to HIV and violence?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• How can equal consideration be given to all women and girls, regardless of background, socio-economic status, ethnicity or lifestyle?</li> <li>• How can budget allocations support the development of medicines, products and vaccines in ways which respond to the issues of HIV and VAW?</li> </ul>

## 4.6 Human resource training

The situation analyses carried out for this project (CIM, 2010 a-d) consistently report that people working in the sphere of violence against women are not adequately trained in HIV, and people working in the sphere of HIV are not adequately trained in responding to violence against women.

Ensuring that integrated training on HIV and violence against women is available to all those working in both spheres is a way to promote the ethical principles of beneficence, non-maleficence, respect and justice, and that the staff of government bodies, NGOs and community organisations have

the capacity to address both issues in an integrated way without causing additional harm. In line with the ethical principle of autonomy, women living with HIV and women who have experienced violence should be involved in providing this training.

When service providers and other professionals are over-burdened, they may be resistant to integration (Luciano, 2007, p. 4). Issues such as staff turnover, which is often high in the public sector, must also be taken into account when developing good quality training on integration of HIV and violence against women.

Policy makers and decision-makers also need to have training on both HIV and VAW, and access to information and data on HIV, VAW and their intersections. This should include women's rights, including the rights of women with regard to violence and HIV, as well as the necessary interpersonal skills and sensitivity to enable them to incorporate women's experiences. A number of initiatives have developed training materials for this purpose, focusing on aspects such as the sexual and reproductive health and rights of women living with HIV (EngenderHealth, 2003; 2006; 2008) and HIV positive motherhood (Salamander Trust, 2008). Other relevant resources include those documenting collaborative work between parliamentarians and women living with HIV (Parliamentarians for Women's Health, 2008), and resources for clinicians working to facilitate peer support for women living with HIV ([www.shetoshe.org](http://www.shetoshe.org)).



<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can training ensure that women – in all their multiple identities - receive empathetic, respectful and non-judgemental treatment from staff, which respects their autonomy, confidentiality and privacy and which guarantees their safety?</li> <li>• How can training be designed which involves those women most affected in the development and delivery of training, in order to recognise women as experts by experience, thus empowering them and increasing their autonomy?</li> <li>• How can training best be delivered to enable women experiencing violence against women and/or living with HIV to improve their livelihood opportunities?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can human resources training guarantee that women will see only benefits, and will not experience any further ill-effects?</li> <li>• When resources are scarce and staff are already overstretched, how will training improve the working life of staff and avoid increasing the burden on them, while ensuring better quality of services from the perspective of women?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• Are adequate budgets allocated to human resource training, and are they distributed with equity and fairness?</li> <li>• How will training ensure that all women see the benefit, regardless of age, socioeconomic status, ethnicity or lifestyle?</li> </ul>

## 4.7 Monitoring and evaluation

Monitoring and evaluation are now standard practice and a requirement across most sectors. However, the way monitoring and evaluation is carried out has ethical implications.

Monitoring indicators established by government departments, financial reporting and evaluation findings tell only part of the story. All too often, qualitative analysis is lacking, meaning that the experiences of those people which an initiative aims to benefit are not captured, and any unintended effects are ignored. Monitoring of programmes to prevent vertical transmission of HIV provide a clear example. It is not enough to count the number of women who enter the programme, or even the number of HIV negative babies born to women living with HIV. Routine antenatal HIV testing is often perceived as compulsory, and at times is carried out without informed consent or even without the woman's knowledge – despite evidence to suggest that partners and families may react violently to this, particularly when the test result is positive. And when the focus of attention is the birth of an HIV negative baby, without providing treatment, care and support to the mother, some of the negative effects of the programme may not be picked up by standard monitoring and evaluation.

It is also vital that monitoring and evaluation should start from the visions and priorities of women and girls living with HIV and/or experiencing violence. Indicators must be used which deepen knowledge and facilitate citizen surveillance of the links between HIV and VAW at different levels (macro, sectoral, community, relationships/family). Participatory monitoring and evaluation – in this case processes which include women living with HIV, women experiencing violence, and women who are vulnerable to HIV and/or violence – enable those women who are most affected to set the right parameters to take into account their priorities and experiences, and provide a channel for their contributions to lead to changes or improvements to the policy, programmes and services in question. Otherwise, crucial opportunities are lost to make consistent progress towards the visions of the most affected women and children.

There are many examples of participatory monitoring and evaluation. Positive Women Monitoring Change is one of these (ICW, 2005). In this project, women living with HIV worked together to develop a tool to monitor access to care, treatment and support; sexual and reproductive health and rights; and violence against women. Developed by and for women living with HIV, the tool was used to collect information from the perspectives of women living with HIV, service providers and policy makers. The tool as a whole is relevant to HIV/VAW integration, and the section specifically addressing violence against women is reproduced in this document in Appendix 2.

When HIV and VAW are present, monitoring and evaluation may often involve sensitive data, which must be handled with absolute respect and confidentiality. Women must be informed about why the data is being collected, where it will be used, and how it will identify them. Better still, they should be involved in the design of the monitoring and evaluation process to ensure that it gathers information on the issues which they deem most pertinent.



<b>Respect for autonomy</b>	<ul style="list-style-type: none"> <li>• How can monitoring and evaluation of integration efforts ensure that all initiatives promote respect for women’s autonomy, diversity, confidentiality, privacy and safety?</li> <li>• How can monitoring and evaluation itself be carried out to that it respects women’s autonomy, diversity, confidentiality, privacy and safety, and ensures their full and informed consent if their data is to be used?</li> <li>• How can monitoring and evaluation include the involvement of those women most affected, to promote their empowerment and increase their autonomy?</li> </ul>
<b>Beneficence</b>	<ul style="list-style-type: none"> <li>• How can monitoring and evaluation be based on the priorities and visions of the women most directly affected by HIV and VAW?</li> <li>• How can monitoring and evaluation be used to ensure that initiatives do as much as possible to improve the situation for women and girls with regard to HIV and violence against women, and to avoid additional harm to women and girls?</li> <li>• How can monitoring and evaluation increase integration of HIV and VAW?</li> <li>• How can monitoring and evaluation be designed to ensure it avoids cultural intrusion while adhering to fundamental ethical values?</li> </ul>
<b>Justice</b>	<ul style="list-style-type: none"> <li>• How can monitoring and evaluation ensure that initiatives and improvements benefit all women, particularly those who have traditionally been excluded?</li> <li>• How can budgets be allocated to ensure that monitoring and evaluation supports integration of HIV and VAW, and is participatory and gender-sensitive?</li> </ul>

This section aimed to provide a context for reflection on the ethical considerations surrounding HIV and violence against women, and suggestions for particular ethical considerations within different sectors. The next section, Section 5, explores integration of HIV and violence against women within the development and implementation of policies and programmes.



Photo: [http://www.flickr.com/photos/michael\\_hughes/1903270036/](http://www.flickr.com/photos/michael_hughes/1903270036/)



## 5. Ethical considerations for integration of HIV and VAW in policy and programme planning and management

This section explores ethical considerations related to the development and implementation of policies and programmes which integrate HIV and VAW.

### 5.1 Implementation of integrated policies and programmes

‘While gender systems can be slow to change, they are often under pressure from other structural processes that challenge the foundations on which the edifice of gender power rests. Some of these processes may indeed shake those foundations, and this can lead to tension, resistance (especially from those who benefit from gender power), accommodation, or transformation.’ (Sen, Ostlin and George, 2007, p. 14)

In the countries involved in the project, there are examples of policies on HIV and/or violence against women which include ethics, gender equality and human rights as cross-cutting issues. However, these do not follow through to the lines of action, the indicators or the monitoring.

When designing and implementing policies and programmes, it is important to bear in mind that these should:

- Be integrated, with participation of all the actors, particularly women who are affected by the issues.
- Focus on protecting human rights and promoting gender equity.
- Use participatory, bottom-up approaches.

- Be cross-cutting, with full coordination between all parties to ensure effective responses.
- Be culturally relevant and take into consideration the possible impact of cultural and religious practices.
- Have adequate funding.
- Be supported by the political will needed to develop policies and allocate resources to promote women's health (including prevention of HIV and VAW) and gender equity.
- Sustainability is crucial. Financial sustainability must be guaranteed through adequate budgetary provision. Political, structural and institutional sustainability is equally important. The integration of HIV and VAW is an issue which must not be affected by changes to the political administration, but must be part of a broader movement toward greater equality, respect for the rights of women and girls, and the creation of a more welcoming and safer world for them.

There is a growing body of evidence, knowledge and understanding of what works for women in relation to policy, programming and service provision in terms of human rights, equality and gender equity ([www.whatworksforwomen.org](http://www.whatworksforwomen.org)). There is also a growing awareness of the importance of involving women in the development, implementation, monitoring and evaluation of policies, programmes and service provision plans. From an ethics of care perspective, this is fundamental to the promotion of empathy and respect for autonomy (Slote, 2007). Any policy or programme on violence against women must take care to analyse its impact on HIV and vice versa. Any initiative related to HIV must bear in mind the possible effects on violence against women. Using the lens of women's vulnerability to violence, HIV, and HIV-related violence, stigma and discrimination can be an extremely useful tool for decision-making in relation to policies and programmes.

A number of tools and resources exist which provide useful guidance for policy makers and implementers with regard to gender and HIV. These are based on sound ethics, and include gender violence as a key consideration in addressing HIV.



These include:

- What Works for Women and Girls: Evidence for HIV/AIDS Interventions, [www.whatworksforwomen.org](http://www.whatworksforwomen.org)
- UN Women (2011) Virtual Knowledge Centre to End Violence Against Women and Girls
- UNAIDS (2010) Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV: Operational plan for the UNAIDS action framework: addressing women, girls, gender equality and HIV 2010-2014
- Pan American Health Organization (2009) Guide for analysis and monitoring of gender equity in health policies
- Parliamentarians for Women's Health (2008) Guide for Community Assessments on Women's Health Care
- ICW (2004b) Visibility, Voices and Visions

## 5.2 Role of people living with HIV and communities

'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, cited in ICW, 2004c)

The participation of women living with HIV and of communities is crucial to advancing collective responses to the challenges of HIV and violence against women (UNIFEM and Athena, 2008). The Paris Declaration (1994) stipulates the need for the Greater Participation of People living with HIV (GIPA) in all decisions which affect their lives. The ethical principle of respect for autonomy underlies the principle of participation: involving women living with HIV or those who have experienced violence in policy and programming decision-making respects them as human beings and agents of change, rather than viewing them merely as 'targets' or 'beneficiaries' of actions.

'La 'participación', cuando tiene lugar, se ofrece como un trato de favor, un premio o un ticket de comida, un viaje con gastos pagados a Nueva York... ¿qué más podría esperar una persona (pobre, sin educación, marginalizada, infectada con el VIH, mujer)? En contadas ocasiones, si es que hay alguna, le preguntan las y los creadores de políticas, organizadores de la reunión o implementadores de programas: '¿cuáles son tus prioridades?, ¿por dónde crees que deberíamos empezar?, ¿cuáles son las principales dificultades con las que te encuentras a nivel local?, ¿de qué crees que va todo esto?'  
(Gatsi Mallet y Orza, 2007)

If participation is to ensure that the principle of beneficence is reflected in decision-making, it must be explicitly supported. HIV positive women have too often been invited to attend policy meetings at short notice and without sufficient time to prepare. There is also a tendency for policy makers to invite the participation of individual women, rather than inviting women's groups to send a representative. Papers for meetings may be sent by email rather than in hard copy, putting the onus on the women participants to organise and pay for printing of what can often be lengthy documents. There are rarely opportunities for women participants to learn about or observe the meeting culture before taking part. This can make it difficult to play a full role, and to adapt to the particular way of working of any given meeting or group. Women participants may find they are a lone voice in the meeting, or may feel they are expected to be 'representative' – whether they are or not. Financial resources to cover the costs of participating are not always made available, or are reimbursed after the event, placing an additional burden on women (ICW, 2004c).

Women living with HIV and women who experience violence must be at the centre of the response. Women who use drugs and women sex workers have important insights into the intersections between violence and HIV, and the most effective ways to address these, as do women migrants, indigenous women, women who are deprived of liberty and others who are particularly affected by the social and structural determinants of HIV and violence against women. Their perspectives, contributions and comments must be sought out in line with the ethical principles of respect for human dignity and autonomy.

However, simply allowing women's participation does not address the issues of poverty, socioeconomic status or vulnerability. An ethical approach requires not only that women's participation is permitted, but that they are provided with the support needed to participate effectively. To this end, it is important that women's organisations are adequately funded and supported.

### 5.3 Strengthening of the sectors involved

The distribution, allocation and prioritisation of resources are ethical issues, as are forms of empowerment such as training and support. An ethical approach to strengthening the sectors involved would require:

- Individual and collective empowerment of affected groups.
- Human resource training for professionals in both sectors.
- Employment and protection of women affected by HIV and VAW in all sectors.
- Community awareness-raising to deepen understanding of the roots of both issues and promote community action to address both.
- Attention to the diversity and complexity of these requirements.
- Resource allocation.

The fundamental ethical principles underpinning all work to strengthen the sectors involved include the participation of women affected by HIV and VAW, and transparency and accountability to affected populations. Projects to integrate HIV and VAW must give high ethical priority to strengthening the organisations of women living with HIV and women experiencing or at risk of violence, in order to support their full participation in policy decision-making, service provision, research (including women as study participations as well as co-researchers involved in the design, implementation, review and publication of research results), and monitoring and evaluation. There is also an ethical imperative to support attitudinal change among policy makers, service providers and professional researchers, among others, so that they collaborate respectfully and on an equal footing with the women who are most affected by HIV and VAW.

## 5.4 Intersectoral coordination

'While we believe firmly in and demonstrate the possibility of transforming unequal gender relations and their effects on health, this report offers no silver bullets or easy panaceas to cure the pervasive and persistent problems of gender inequality and inequity. The devil, so far as gender equity is concerned, is often in the details of governance structures and organisational processes.'

(Sen, Ostlin y George, 2007, p. 4)

Given the intersections between violence against women and HIV, which are rooted in the same structural and social determinants and the same inequalities, inter-sectoral coordination is of enormous importance. It is without doubt absolutely necessary to guarantee that women living with HIV have access to antiretroviral treatment. However, if this is done without also ensuring that women have access to the transport they need to get to hospital, the money to pay for this transport, the ability to take time away from work, childcare and other obligations to attend clinic appointments, and trust that their right to confidentiality will be respected, then it is likely that women in violent relationships could be exposed to further harm.

Similarly, in the absence of inter-sectoral coordination, women living with HIV or experiencing violence may face significant challenges in accessing services which meet their needs, which are welcoming and which can offer support in relation to both HIV and violence. They may also find it difficult to find or remain in work, to get legal redress, safe housing, or emergency responses which are able to meet their needs. They may also be exposed to increased violence as a result of economic insecurity, and lack of or precarious housing.

Inter- or multi-disciplinary work which has the full participation of women living with HIV and women experiencing violence is of vital importance for the development of policies and programmes which are able to address both issues in an integrated way.

Key ethical considerations in relation to inter-sectoral coordination include:



- Responsibility of decision-makers and programme implementers to analyse and foresee the impact of particular aspects that any one area of work will have on others. Organisations, agencies and institutions working on HIV cannot ignore the effects which violence against women, poverty, unequal access to resources, access to rights, etc. have on the spread of HIV.
- Review and analysis of contradictory public policies.
- Policies and programmes must be mutually reinforcing.
- Creation of channels of communication and improved decision-making processes.
- Consistent analysis of possible scenarios and alternatives.
- Anticipation of the results and consequences of policy decisions.

## 5.5 Sustainability

Sustainable development is ‘development that meets the needs of the present without compromising the ability of future generations to meet their own needs’ (Brundtland, 1987). Human development is linked to gender equity and full access to human rights. It is also linked to progress towards the elimination of violence against women and HIV.

Sustainability includes social, natural, economic and institutional sustainability. It depends on maintaining a holistic vision – it is not possible to make partial gains in sustainability, but rather the system as a whole must be sustainable. It is not possible to enjoy some rights at the expense of others – they all form part of the same system. Nor can some population groups be placed above others.

Humanity as a whole must be taken into account, through measures which contemplate different dimensions and systems, and which are not just one-off economic or political initiatives.

The construction of a cohesive social fabric will have the long term effect of enabling the full development of the whole community, including women

living with HIV or at risk of acquiring it, in which violence is no longer at the centre of relationships.

The sustainability of HIV and VAW integration depends on a number of factors. The situation analyses and actor mappings carried out in the project countries (CIM, 2010<sup>a-h</sup>) have identified some of the current strengths and key organisations. Further work must build on these strengths, and on the existing expertise in governmental and civil society organisations. The need for accountability, transparency, and good inter-sectoral partnership working is something of a cliché, yet is hard to achieve. The disciplinary divide that exists between sectoral experts, and the ideological and opportunity gap between people working in government agencies and those in civil society organisations, can make for tense relationships. Importantly, the lack of respect for 'expertise by experience' which is common among professionals is a real stumbling block for sustainability of an initiative which depends on a deep understanding of the realities of women's lives.

Funding is also key to sustainability, and must include resources for civil society organisations focused on HIV and violence against women. Wherever possible, grant funding should respect the principle of autonomy, and should be flexible enough to fund the development of the organisation, and not just specific projects.

More than anything, sustainability will depend on the solid commitment - across all sectors and by all those involved - to shared values and a common trust in concepts such as human rights, gender equity and equality of all.



## 6. Conclusion

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It is not possible to detail here the variety of situations in which a lack of ethical analysis could lead to the very policies, programmes and interventions designed to improve a situation ultimately perpetuating or increasing the risk to those affected. A list of priority issues for action is below, drawn from discussions within the forum at which the draft of this document was presented (October 2011).

- Ongoing integration and collaboration between work on violence against women and HIV.
- Creation of environments which are free of violence and prejudice and which can be easily accessed by women and girls.
- Education: comprehensive sex education from early years is fundamental. Educating people to value and respect human life in all its diversity is also key.
- Integrating ethics into the curriculum for professionals in universities and other educational centres.
- Participation of women affected by HIV and violence to contribute their expertise at all levels.
- Empowerment of women must not be limited to one-off individual opportunities but must be accompanied by social change aimed at creating environments in which such empowerment becomes a reality.
- Highlighting the role of men within and through institutions. It will be impossible to progress towards an egalitarian society unless men accept their collective and individual responsibility for social change. Non-violent masculinities must be developed.
- Equitable distribution of resources to enable programmes and policies responding to HIV and VAW to be implemented in their integrity.
- Fulfilment of the commitments signed up to in national and international agreements.
- Ethical processes to be applied to all initiatives, from direct interventions to the design of laws, policies and programmes.

As stated in the introduction, this document aims to be a living tool which provides a guide to the ethical analysis and decision-making processes



involved in developing and implementing programmes and policies which integrate HIV and VAW.

Like human rights, ethics only comes alive when it is translated into practice and adopted, promoted and unpacked by professionals across the sectors which have direct or indirect links to HIV and VAW. The application of ethics is not optional; it is the duty of us all, as members of the society in which we live, and the particular responsibility of those people who act as social change agents and have other people in their care.

# Appendix 1

## Health Systems Reform for Integration of Violence against Women and Girls and HIV

Health Systems Reform		
Recommendation for Programming on Violence against Women and Girls and HIV		
Violence against Women and Girls	Both Violence and HIV	HIV
<ul style="list-style-type: none"> <li>• Prepare protocols and develop and implement training on victim-friendly forensic examination.</li> <li>• Collect and monitor sex and age disaggregated data on GBV and domestic violence.</li> <li>• Guarantee free access to 24-hour sexual assault services, including psychological support services, STI treatment, post-exposure prophylaxis, and emergency contraception.</li> </ul>	<ul style="list-style-type: none"> <li>• Create and implement training for all health providers on HIV and GBV screening, treatment, danger assessment and safety planning, and emotional support, including with children.</li> <li>• Create standards for upgrading infrastructure of health facilities to ensure confidentiality and privacy.</li> <li>• Ensure access to treatment for GBV and HIV by addressing women's and girls' mobility, distance from clinics, safety issues around transport and overall cost of travel; consider mobile and decentralized treatment centers in rural areas as well as home visits by health/social workers.</li> <li>• Providers should be trained in rights-based approached, including codes of conduct informed choice and consent, and</li> </ul>	<ul style="list-style-type: none"> <li>• Collect and monitor sex and age disaggregated data on HIV.</li> <li>• Train VCT counselors to monitor for GBV and ask questions about partner violence, develop safe disclosure plans, and expand couples counseling and testing.</li> <li>• Address the problems of obtaining and adhering to ARVs for women who suffer IPV, through for example including questions on adherence monitoring forms that explore IPV.</li> <li>• Ensure the female condom is available in addition to the male condom.</li> <li>• Ensure treatment of AIDS-related illnesses and opportunistic infections; treatment information and adherence; prevention and treatment of sexually transmitted diseases; nursing, home and</li> </ul>

	<p>confidentiality and disclosure.</p> <ul style="list-style-type: none"> <li>• Ensure GBV and HIV staff has adequate resources, such as screening tools and directories to refer victims to other services, including legal or counseling services.</li> <li>• Integrate GBV services into antenatal, STI, HIV and family planning services.</li> <li>• Ensure that children and adolescents have equal access to child and youth friendly health services.</li> <li>• Ensure that PEP is available not only to sexual assault survivors, but also as part of a comprehensive sexual and reproductive health service available for women whose partners are living with HIV and who may have engaged in risky sexual behavior.</li> </ul>	<p>palliative end-of-life care; prevention of MTCT.</p> <ul style="list-style-type: none"> <li>• Ensure availability of prevention services (counseling, HIV testing)</li> </ul>

Ward, J., 2008.

# Appendix 2

**Extract from Positive Women Monitoring Change (ICW, 2005), a participatory tool developed by women living with HIV**

## Section 4

### Violence against women (VAW)

#### 1. Knowledge

What do you understand by the term “Violence against women”? In what ways do you think HIV/AIDS and Violence against Women are related? Are you familiar with any policies, legislation, or international agreements which address VAW? What impact do you think they are having? Do you think they are effective? How would you describe women’s position in this society? What services are you aware of which assist women who have experienced violence including rape? Are the services free and accessible (medication expenses, legal representation)?

#### 2. Experience of violence against women

Has fear of violence ever prevented you from seeking care, treatment or support, acting on medical advice, or negotiating safe sex practices in your sexual relationship(s)? Please give details. What forms of violence have you experienced? (If none, please go to the last section on change) Have you experienced an increase of violence since your disclosure? Do you feel that the violence you have experienced was due to your HIV status or gender? Please give examples.

#### Definition

Violence against women (VAW) can take many different forms including verbal, physical, sexual, emotional, financial, and psychological violence. It can also take the form of fear of any of the above. The understanding of the term as used in the workshops in which this tool was developed, includes the following types of violence or fear of these: Rape; incest; statutory rape (sexual intercourse with children or young people below the legal age of consent); marital rape; refusal to use available protective



technologies to safeguard against (re-)infection or transmission of STIs including HIV; domestic violence; battery and assault; verbal violence or bullying such as cursing and use of swear words and derogatory terms; sexual violence including sexual intimidation or threats; stigma and discrimination; refusal of medical examination or treatment; withdrawal of financial support; abandonment; community violence (e.g. setting fire to someone's house); violation of human rights; being deprived of access to and ownership of property after the death of spouse.

### **Interview tip**

We have found that when using the questionnaire, it can be intimidating to go through all the questions.

You may prefer to start a 'conversation' with a general question related to each (sub-)section which will elicit a story from the person you are interviewing and get them talking. After a more general conversation, you can use the questions as a check list to see whether any key areas of information have been missed.

### **Example question**

Can you tell me about your experiences of violence against you or HIV positive women or girls that you know? This may also include experiences of services, information and referrals.

### **Asking personal questions**

Some people may feel that the questions in this section are too personal to ask or answer. If you or your interviewee feels this way, you could ask the questions in the third person, for example: What types of violence are commonly experienced by HIV positive women in your community, and what is the impact on their health and ability to access health care and other services?

## VAW: Questions for positive women

Who did you go to for support after experiencing violence? (E.g. family members, friends, community members, police, church, support group, counsellor, etc)

### 3. Experience of services

Have you ever

1. Reported an incidence of violence to the police?
2. Sought medical help?
3. Sought legal advice?
4. Had counselling related to violence?
5. Sought support from community groups including support and church groups?
6. Sought support from family and friends?

How comfortable were you with these services and support? How were you treated? What were you offered? What could have made the experience easier or more comfortable? Which did you not approach and why? Please describe your experiences of accessing any of the above services and support.

### 4. Barriers

What barriers did you encounter in accessing any of the services and support mentioned above (for example, money, transport, or fear of negative consequences)?

### 5. What needs to change?

What changes are needed to improve services and support for HIV positive women who experience violence in your area? How could services better suit your needs and address your concerns as an HIV positive woman?

Please describe your experience of accessing the following, when reporting violence

- Post exposure prophylaxis (PEP)
- Legal advice and assistance
- Referrals (medical, legal, counselling etc)
- Counselling
- Medical examination / report
- Financial assistance
- Safe house
- Female police officers / medical staff
- Special room for interrogation
- Other

## VAW: Questions for service providers

(This section is meant for people working in the following areas: Police, clinics, hospitals, NGO (with a VAW mandate), support groups and legal support organisations)

### 1. Services

What do you understand by the term Violence against women? What services do you provide for women who have experienced violence against women? How are these services tailored to address the particular concerns of HIV positive women (e.g. how do you create an environment in which an HIV positive woman can talk openly about her status and experience of violence)? Do you offer any services to couples? Do you ever encourage women to return with their partner? What kinds of violence can women report here? What forms of violence are most commonly reported here?

### 2. Procedures and referrals

What procedure do you follow if a woman who is HIV positive comes to report an incidence of violence? Do you offer medical advice / services? If not, is a referral made on behalf of the service user? Do you offer legal advice / services? If not, is a referral made on behalf of the service user? Do you offer counselling services? If not, is a referral made on behalf of the service user?

Do you have a policy or programmes to protect the service user from further violence (e.g. safe houses, perpetrator rehabilitation, restraining orders)? Please give details. How do you monitor the speed and effectiveness of referrals and follow-up actions? What procedure exists for a woman to make a complaint about the service?

### **3. Legal action**

How often do the cases go to court? Of these how many result in convictions? What is the average time frame from reporting the incident to sentencing a perpetrator of violence? How often do women withdraw or drop cases after they have initiated a legal process? What are the reasons for this?

### **4. Resources / quality of services**

What training on HIV and VAW do service providers receive? Do they include information and counselling on PEP? What do you do to make the experiences as comfortable as possible for the women who report incidences of violence? How do you ensure women friendly services and positive attitudes among the police, health workers, counsellors, etc? What constraints do you face in protecting the rights of HIV positive women who have experienced violence?

### **5. GIPA**

How are HIV positive women involved in the consultation, design and implementation of all relevant policies and legislation? Are they paid staff or volunteers? What government supported programmes or services are there that address the needs and rights of positive women on which HIV positive women were consulted?

### **6. Future plans / What needs to change?**

What additional resources do you need to address the needs of HIV positive women who have experienced violence? What are your plans to improve the services for HIV positive women who have experienced violence? In what way does your service help to reduce the rate of violence against women, in particular HIV positive women?



## **1. Existing policies**

What government policy exists on women's rights, gender, violence against women, including policies to revise customary and cultural practices, such as forced marriages, virginity testing, mourning rituals for widows, and others which violate HIV+ women's rights, or related policies, legislation and resources? What are the international agreements and declarations to which the government is signatory (e.g. CEDAW, etc), and related policies, legislation and resources?

What are the national strategic plans addressing the rights and concerns of HIV positive women, mitigating the impact of the epidemic, and related policies, legislation and resources? Which ministries, departments, and bodies are responsible for making and implementing laws and policies on women's rights in general and VAW in particular?

## **2. Budgets**

What is the budget allocation for issues relating to VAW and violence against HIV positive women under the ministry of 1) justice, 2) home affairs 3) health?

## **3. What has been done – programmes, policies, support etc**

What government supported programmes are there to reduce violence HIV positive women in the country? How many institutions address violence against women and how?

## **4. Campaigns**

What government backed campaigns are there that raise awareness about women's rights, and violence against women, particularly in relation to HIV and AIDS, in the media, through poster campaigns, in schools, etc? What information has been produced and disseminated by the government on violence against women and women's rights? Who are the target audiences of awareness arising campaigns?

## **5. Monitoring**

What indicators and reporting procedures are used to monitor policy

instruments such as CEDAW? What are the procedures for reporting on VAW to international community? What methods and mechanisms exist for measuring and disseminating national statistics relating to VAW?

## **6. GIPA**

How have HIV positive women been involved in drafting gender policies or related policies? What mechanisms exist for ensuring the participation of HIV positive women are included in decision-making that affects their lives? How are HIV positive women involved in implementation and monitoring of international policy commitments that concern them?

## **VAW: Questions for government**

### **7. Future plans**

What are the government's plans to develop, update and implement any draft policies relating to gender, women's rights or violence against women? What are the government's plans to develop new policies, programmes and legislation to stop violence against women, including violence against HIV positive women?

What level of civil society involvement is there in the development and sharing of these plans including HIV positive women's groups? What resources does the government plan to provide for providers of services for HIV positive women who experience violence in the coming 12 months?





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**Ethical considerations  
for an integral response to  
human rights, HIV and violence  
against women  
in Central America**



Organization of  
American States



Inter-American Commission of Women

