Unit 4: Parliamentary Response to HIV/AIDS

Learning Objectives

How do parliamentarians contribute to the response to HIV/AIDS?

After studying this unit you should be able to:

- Have a better understanding of the rationale for strong parliamentary leadership on HIV/AIDS;
- Know the challenges and obstacles that parliamentarians face in their response to HIV/AIDS;
- Have a basic understanding of the role of parliamentarians and key steps for parliamentary action against HIV/AIDS.

Introduction

As elected officials parliamentarians have a responsibility to address the needs of their constituencies, more often this means meeting the needs of people living with HIV/AIDS. This not only includes advocating for and developing protective legislation, and diverting public funds to HIV/AIDS campaigns, but also setting a positive example by speaking openly and honestly about the disease. Parliamentarians can be leaders and role models in their constituencies by denouncing stigma and discrimination, promoting testing, prevention, and treatment, and ensuring equal opportunities for political participation among those living with, or affected by HIV/AIDS.

Unit 4 provides an overview of the roles and responsibilities of parliamentarians in the fight against HIV/AIDS and explores the rationale for stronger parliamentary engagement in the response to the pandemic. This unit identifies how MPs can play an active leadership role on HIV/AIDS through their core lawmaking, oversight, and representation functions.
This unit looks more broadly at the leadership role of parliamentarians, as an introduction for subsequent units that delve into the specifics of HIV/AIDS legislation, budgetary oversight, committee work and outreach initiatives in more detail.

**Why Should Parliamentarians Play a Key Role in the Response to HIV/AIDS?**

As has been introduced in previous units, strong leadership is required to effectively combat the pandemic. The greatest achievements in preventing the spread of the disease and alleviating the impact of HIV/AIDS has been found in countries where the political leadership has demonstrated strong political will and a firm commitment to prioritize, acknowledge and respond to the crisis openly.

In some countries, the executive branch of government has taken the necessary leadership role to respond to the crisis and ensured that a multisectoral approach was undertaken in the fight against the disease. However, other countries have suffered from the lack of leadership and commitment from political leaders who have largely ignored or avoided the issue, or have not spoken truthfully on the facts about HIV/AIDS. Countries such as Brazil, Cambodia, Senegal, and Uganda are known for their strong political leadership on HIV/AIDS in terms of both treatment and prevention efforts, while other countries such as China and South Africa have demonstrated weak responses to the pandemic (see unit 1 and 2 for more information and examples). Consequently, rates of HIV infection and disease outcomes continue to rise in these countries. Regardless of the level of involvement of the Executive in the fight against HIV/AIDS, parliamentarians have an important leadership role to play in the response to the pandemic.

"Let us give publicity to HIV/AIDS and not hide it, because that is the only way to make it appear like a normal illness."

_Nelson Mandela, Former President of South Africa, who publicly announced that his own son died of AIDS_
As a nation’s legislative body, parliamentarians have the responsibility to enact laws that will protect the rights of those affected by HIV/AIDS such as, people living with HIV/AIDS (PLWHA), orphans, and vulnerable groups. They must also ensure that legislation exists to ensure equal access to healthcare, education and other social services for all citizens. Because parliamentarians also hold the purse strings of government and are mandated to review and approve the national budget, they are the key players in influencing what percentage of the overall budget is allocated to health care and specific programs to fight HIV/AIDS. As representatives of the people, parliamentarians also have a duty to speak out about HIV/AIDS and confront the stigma and taboos in a very public manner.

The global response to HIV/AIDS has intensified in recent years and governments all over the world have committed to several declarations and targets to respond to the pandemic including the Declaration of Commitment on HIV/AIDS, the Abuja Declaration, and the Millennium Development Goals (See Unit 3 – Global Responses to HIV). In this environment, parliamentarians have a critical oversight role to play in order to ensure that the targets outlined in the aforementioned documents are met and that national programs and policies are in place to implement strategies to reduce the spread and impacts of HIV/AIDS.

Although there are significant commitments and pledges to the fight against HIV/AIDS and important progress has been made in several countries to increase the national response to the pandemic, there remain fundamental problems in fulfilling international commitments and implementing policies and programs. Some countries may have achieved great improvements in access to treatment and antiretroviral drugs (ARVs) but may still be lacking in adequate legislation to protect the human rights of people living with HIV/AIDS (PLWHA). Other countries may have developed strong education and prevention programs but not allocated sufficient resources in their health budget to offer equal access to treatment. International funding for AIDS has increased but problems with corruption and misuse of funds have curtailed efforts in certain countries.

The challenges to overcome are serious:
• Although there have been marked increases in access to ARVs, many people living with HIV in low- and middle-income countries still lack access to these life saving medications. For example, even though 3 million individuals in low- to middle-income had access to ARVs in 2007, this only represents 31% of those in need. In addition, only 33% of HIV-positive pregnant women had access to medicines to prevent mother-to-child transmission globally in 2007, and only 15% of children in need of treatment actually received it;

• Evidence still demonstrates that children are significantly less likely than adults to receive treatment. Without treatment half of all children infected with perinatal HIV will die by the age of two, despite this statistic children are only one third as likely to receive treatment as adults;

• The number of new HIV infections continues to outstrip the increase each year in the number of people on antiretroviral drugs by 2.5 to 1. Thus, the long-term sustainability of even the current pace of treatment scale-up may be jeopardized;

• National health budgets in low-middle income countries in Africa fail to meet the Abuja Declaration 15% target;

• Stigma and discrimination against people living with HIV is ubiquitous and there is a lack of protective legislation for such vulnerable groups such as sex-workers, injecting drug users, and men who have sex with men. Weak legislation that addresses these groups have left to the abuse and discrimination of vulnerable groups at high risk to HIV infection;

• Countries are struggling to address the growing problem of HIV orphans;

• HIV is a social and cultural issue and many governments have failed to promote and encourage dialogue among populations on sensitive issues such as gender equality, sexual and reproductive health or homosexuality;

• Countries most affected by HIV will fail to meet other *Millennium Development Goals* and are already suffering from weakened development and poor economic growth as a result of HIV/AIDS.

Parliamentarians are in a unique position to play a leadership role to overcome these challenges because of their three key roles within the legislature:
Parliamentarians as Lawmakers
As lawmakers, MPs have the duty and responsibility to develop, review and enact legislation that will strengthen the response to HIV/AIDS. Examples include human rights laws prohibiting discrimination against PLWHA, health laws to ensure HIV treatment for all in need and trade laws to remove barriers for access to generic drugs. MPs have a duty to ensure that HIV/AIDS remains a priority on the legislative agenda.

Parliamentarians as Representatives
As representatives of the people, MPs reach out to their constituencies and play a very public role where they can raise awareness about the disease and speak out against the stigma and discrimination. MPs are also in a unique position to undertake public consultations to collect and incorporate the needs and priorities of the population in the policymaking process.

Parliamentarians as Overseers
The oversight role of MPs is fundamental to Parliament’s engagement in the fight against HIV/AIDS. MPs have the mandate to oversee government activities and to hold the Executive accountable for its actions. MPs can investigate whether government are respecting their international commitments on HIV, whether adequate policies and programs are in place and whether services are reaching the most vulnerable and at risk in society. As overseers of the national budget, MPs effectively control how much funding is provided to AIDS programs as well as to the overall health and education sectors for treatment and prevention programs.

Current Barriers and Limitations for Parliamentarians in their Fight against HIV/AIDS
Despite the constitutional mandate parliaments have to represent lawmaking and oversight functions, and the obvious contribution MPs can make to the effectiveness of the HIV/AIDS response, the reality is that too few legislatures are at the forefront of national responses to HIV/AIDS. Governments rightly lead the response to HIV/AIDS and they often involve non-state actors such as civil society to assist with the
implementation of programs. But few parliaments have exercised their duty to monitor government business on HIV/AIDS.

The question has been raised as to why parliamentary responses to HIV/AIDS been largely insufficient in terms of public advocacy. In response, MPs identified several limitations and challenges that inhibit their leadership role on HIV/AIDS:

**Strategic Vision vs. Political Endurance**

Most elected representatives operate on short-term agendas tied to their four or five year election cycles. The need to survive the next election conflicts with the demand to serve posterity. In other words, subjects like HIV/AIDS that appear too controversial, sensitive or demand longer-term solutions will be less attractive in terms of personal commitment by the legislator and will less likely feature in parliamentary debates unless they are perceived to have a direct linkage to political endurance and voter support. The lack of political will to truly engage on this issue within parliaments is an important factor in the lack of parliamentary leadership on HIV/AIDS.

**Stigma Attached to HIV**

The stigma and shame attached to the disease make it a sensitive and sometimes politically unattractive issue to champion. On a personal level, being HIV-positive is still a risk for political figures. Even in countries with generalized epidemics, parliamentarians living with the disease or with family members with the disease will not disclose their HIV status to the public, possibly fearing that their positive status could have a negative impact on their political career.

**Weak Oversight**

Most executive branches have not developed a relationship of accountability with their parliaments in matters relating to HIV and AIDS. Conversely, Parliamentarians have considered the problem as an inherent health issue, requiring intervention primarily by the executive. This challenge is exacerbated by the fact that many legislatures are not in

```
“I wanted to win (the 1994 elections) so I stopped talking about AIDS”
Nelson Mandela
```
a position to effectively monitor and control government action, whether it be on HIV or other programs, because of lack of technical expertise and resources and the unwillingness of the Executive to make information available to MPs.

**Absence of HIV Committees**

Theoretically, the parliamentary committee system should play an important role in interrogating government programs more critically and analyzing key legislation with regards to HIV/AIDS. Traditionally, health committees have been tasked with issues related to HIV/AIDS. However, in a multisectoral approach HIV/AIDS should be looked at through a variety of lenses within Parliament. It is for this reason that the Southern African Development Community Parliamentary Forum (SADC-PF) has motivated its member parliaments to establish special select committees to address HIV/AIDS and raise the profile of the disease within the legislatures. These member parliaments are Angola, Botswana, Lesotho, Malawi, Mauritius, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Zambia, and Zimbabwe. Given the magnitude of the pandemic globally and not only in the SADC region, this approach is warranted for all legislatures. Unfortunately very few parliaments have established HIV parliamentary committees and HIV issues continue to be seen only through a public-health lens by legislators, and only some of the time. In addition, membership in portfolio parliamentary committees is determined by the political leadership, which rarely considers the commitment of members to HIV-related issues.

**Lack of Institutional Response**

Few parliaments have recognized and fully investigated the impact of HIV/AIDS on parliament as an institution and on its individual members. Very few parliaments have workplace programs for MPs or staff, nor are training initiatives and resources available to MPs and staff to better understand the disease and its impacts. Members are not adequately trained on the basic facts of HIV/AIDS nor do they have the tools to conduct legislative analysis and oversight functions on HIV/AIDS programs. MPs often identify inadequate financial resources, scarce human resources and insufficient education as an impediment to their work on HIV/AIDS.
**Actions for Stronger Parliamentary Engagement on HIV/AIDS**

Although some parliamentarians have been exemplary as leaders in the fight against HIV/AIDS, the reality is that many legislatures today are not working to their full potential in the response to HIV/AIDS. Despite national commitments and adherence to international conventions to combat HIV/AIDS, the legal framework in many countries has not been updated to meet these international demands and to protect human rights of those infected and affected by HIV. National health budgets are not adequate to meet the demands for treatment as well as maternal health care and stronger sexual and reproductive health programs. Stigma and discrimination is widespread and too few political leaders have taken a leadership role to break the silence and raise awareness about the disease. Conversely, leaders such as Yoweri Museveni (See Unit 2 - The Impacts of HIV/AIDS) and Nelson Mandela have come to embody what it means to be a strong leader in the fight against HIV/AIDS.

---

**Box 1**

**UNAIDS Praises Mandela’s Bold Stance on HIV and AIDS**

Nelson Mandela continues to be an icon in the struggle against HIV and AIDS through his unwavering and outspoken stance on stigma and discrimination towards those living with and affected by the epidemic. “Mr. Mandela’s public acknowledgement that his son Makgatho Mandela, had died from an AIDS-related illness is a demonstration of the practical leadership that Mr. Mandela gives to the international efforts to fight stigma and discrimination,” said Peter Piot, Executive Director of UNAIDS.

Mr. Mandela is one of the many southern African leaders, including his wife Graca Machel, former South African Home Affairs Minister Mangosuthu Buthelezi, and former Zambian President Kenneth Kaunda, who have openly acknowledged the impact of HIV and AIDS on their own families. The openness of these southern African leaders highlights that HIV and AIDS knows no boundaries, and that increasingly all people in this region of the world are being affected by the pandemic.

*Source: UNAIDS Press Statement, January 7th, 2005*

**Recommendations to Enhance Parliamentary Action**

The global impact of HIV/AIDS on economic progress and political stability should make the pandemic a priority for all governments and all legislatures. There are several measures that MPs can take to enhance their level of action and engagement in the response to HIV/AIDS. The following are some general recommendations for actions (further details and resources are available in subsequent units):
Legislative

- **Protecting Human Rights** Parliaments can review and amend relevant legislation affected by national AIDS policies in order to ensure that the rights of those affected by HIV/AIDS are protected including people living with HIV and orphans;

- **Promoting Gender Equality** Legislation should also be reviewed or enacted to address gender-based inequalities, which worsen the epidemic among women. Particularly, MPs should review laws to protect women from harmful traditional practices, from violence and rape and legislation that promotes better economic and social development among women such as inheritance laws, education and access to credit;

- **Improving Access to Drug Treatment** The legal framework must be updated to reform national intellectual property legislation and national patent laws to promote access to affordable generic HIV drugs. The promotion of Universal Access to Comprehensive Treatment, Care and Support by 2010 (see Unit 3) must be sustained;

- **Creating an HIV Focal Point** Establishing a separate parliamentary committee on HIV/AIDS in every parliament can ensure that HIV is not overlooked or regarded only as a health issue. Such a committee can analyze and review all legislation related to HIV/AIDS and also coordinate the multisectoral approach of parliament in its response to HIV.

---

**Box 2**

**What can Parliamentarians in high-income countries do?**

- Advocate for increased bilateral official development assistance (ODA) budget support to the health sector;
- Discourage the use of recruitment policies that explicitly entice health workers from low-and middle-income countries;
- Ensure that trade sanctions are not threatened or imposed by government of low-and middle-income countries that use the TRIPS flexibilities for greater access to affordable generic HIV drugs;
- Promote the development of HIV vaccines and women-controlled prevention methods, such as microbicides.

*Source: Taking Action Against HIV, 2007*
**Oversight**

- **Financial Oversight** Through the budget process, parliamentarians are in a unique position to influence and determine the level of funding designated for HIV/AIDS programs as well as to the health and education sectors to meet national and international commitments to the AIDS response;

- **Aid Effectiveness** The budget process offers an opportunity to scrutinize the level of international donor funding for HIV programs and to ensure that these funds are utilized properly and with results;

- **Oversight of National Strategies** Oversee the work of national AIDS authorities to ensure that they develop long-term strategies that respect international commitments taken by governments such as the *Declaration of Commitment on HIV/AIDS*;

- **Control Corruption** Conduct investigative hearings and field enquiries into HIV/AIDS programs to ensure that national programs are implemented properly, funds are not diverted, and vulnerable groups are receiving access to such programs.

**Representation**

- **Advocacy** Parliamentarians as leaders in the community have an important advocacy and educational role to play in raising awareness about HIV/AIDS and speaking out against the stigma and discrimination;

- **Breaking the Silence** For parliamentarians who are HIV-positive, taking the bold step of declaring their status is a major step in bringing the disease into the open and impact how the public perceives and treats people living with HIV. All parliamentarians can provide a strong example by getting tested and publicly disclosing their results in order to promote awareness about the importance of HIV testing and counseling;

- **Community Outreach** Parliamentarians can be active at the constituency/community level on HIV/AIDS by meeting publicly with people living with HIV and demonstrating an understanding of how the disease impacts their lives. This understanding should inform decision-making in parliament;
• Community Support Parliamentarians are often involved in community projects both in terms of their time and financial support. They can choose to focus on HIV programs and mobilize financial resources and human capital to help these programs prosper.

Other Useful Tools and Mechanisms
In addition to the actions for stronger parliamentary engagement in HIV/AIDS, there are several additional tools that would benefit parliamentary involvement in HIV/AIDS advocacy and prevention. These include:

Knowledge and Capacity Building
Training opportunities for MPs on the complexities of HIV and its policy implications should be more broadly available and more widely utilized. Such training and better access to information and expertise could greatly improve the quality and quantity of legislative interventions on HIV/AIDS. Where these resources are unavailable, parliamentarians should demand them.

Parliamentary Collaboration and Partnerships
Informal collaboration within a parliament through the creation of a caucus or network is often a valuable tool to bring together those MPs most interested and dedicated to an issue. An HIV parliamentary group is different from a committee with formal legislative responsibilities and it also has more flexibility in terms of membership and working in a more non-partisan and inclusive manner. HIV parliamentary groups or networks can also engage in advocacy work in a way that a parliamentary committee may not. These groups can be active within parliament as well as with grassroots efforts working with civil society and people living with HIV/AIDS.

Box 3
Examples of Parliamentary Networks at National Level

United Kingdom All-Party Group on AIDS
The UK All-Party Parliamentary Group on AIDS was established in 1986 and aims to raise awareness of HIV in the United Kingdom’s Parliament and to encourage balanced policies based on accurate information. It ensures that HIV is kept on the political agenda through debates and
questions in the House of Commons and the House of Lords. It acts as a bridge between Parliament and the statutory and voluntary sectors, providing a forum for the exchange of information. It produces briefing papers on topical issues for parliamentarians and an Annual Review summarizes current activities and objectives.

In 2001, the group held a parliamentary inquiry to look at the UK Government’s policies relating to the International Guidelines on HIV/AIDS and Human Rights. The report highlighted how the UK Government has failed to address the impact of its laws and policies on those infected with, affected by and vulnerable to HIV and AIDS. In 2006, the Group also invited nongovernmental organizations (NGOs) and individuals to assist them in conducting a human rights audit of the current policies of the UK Government in relation to HIV with a focus on how domestic practices and policies on HIV and AIDS adhere to the national and international legal obligations imposed by international human rights law and the Human Rights Act 1998, as well as to examine how far its recommendations from 2001 have been put into practice.

**Tanzanian Parliamentarians’ AIDS Coalition (TAPAC)**

TAPAC was established in 2001 by a group of concerned MPs with the objective of mobilizing MPs and officials both at the national and community levels to strengthen the national response. Membership is open to former and serving MPs from all parties and now consists of nearly 80% of all MPs. TAPAC is set up as a non-governmental organization, and hence not formally part of the parliamentary system. By depoliticizing HIV/AIDS, this structure has proven a practical way to deal with issues such as stigma and discrimination. TAPAC has enabled MPs to interact with constituencies and AIDS bodies, as well as enhanced their advocacy role. For example, TAPAC engages people living with HIV as advisers and organizes regular roundtable meetings with them to discuss issues and TAPAC members also meet people living with HIV in their constituencies on a regular basis. In addition, TAPAC has contributed to placing HIV/AIDS on the main political agenda and influenced the parliamentary leadership to take increased responsibility to address the epidemic in Tanzania.

**India Parliamentarians’ Forum on HIV and AIDS**

An All-Party Parliamentarians’ Forum on HIV/AIDS (PFA) was formed in March 2000 to raise awareness about HIV/AIDS and enhance the engagement among the elected representatives at national, provincial and regional levels in India. The forum is engaged in strengthening and supporting the response to the epidemic by reinforcing and sustaining parliamentary leadership and PFA’s actions have included: reaching out to State Legislators and forming State Legislators’ Forums on AIDS in several States; participating in the Colloquium on HIV/AIDS: The Law and Ethics; putting together a Study Group on the Role of Parliamentarians in Combating HIV; and organizing a face-to-face meeting with people living with HIV.

**Brazil Parliamentary Front for Health**

In Brazil, 50 parliamentarians from across the political divide formed the Parliamentary Front for Health. They work together to ensure that AIDS is kept high on the political agenda and to break down prejudice and stigma.


Parliamentary networks also exist at a regional or international level (see Unit 3). They provide unique opportunities to share lessons learned and best practices between MPs
and offer support for MPs who may face opposition and criticism for their advocacy work on HIV/AIDS. Parliamentarians may also seek collaboration with research institutes to gain access to key information and data on the disease while also looking to international HIV agencies and national donors (such as CIDA, USAID, DFID, Sida) for support for their initiatives.

**Collaboration with Civil Society**

In light of the limited financial and human resources of parliamentarians to undertake research and analysis or to conduct field work, MPs can develop innovative partnerships with civil society to gain access to technical expertise, grassroots exchanges and reports on the situation at a grassroots level. In particular they can work with AIDS service organizations (ASO) or with associations of PLWHA (Taking Action against HIV, 2007).

**Box. 3**

**What Should Parliamentarians Do?**

1. Ensure that they are informed about HIV/AIDS, act as advocates for those infected and affected and demonstrate an openness of approach in dealing with HIV/AIDS.
2. Vocalize to reduce stigmatization, social taboos, and discrimination by helping to make HIV/AIDS a visible issue and addressing the myths and facts of HIV/AIDS.
3. Address poverty issues that are intrinsically linked with HIV/AIDS.
4. Visibly demonstrate their political will and commitment to ending HIV/AIDS.
5. Encourage other parliamentarians and political leaders to join national HIV/AIDS bodies and provide support.
6. Involve faith-based organizations, NGOs and community-based organizations in addressing the issues of HIV/AIDS.
7. Consult and involve people in decision-making, especially vulnerable and marginalized groups
8. Encourage the use of peer counselors to facilitate access to information.
9. Effectively utilize parliamentary processes to provide for increased accountability and oversight.
10. Establish all-party groups or caucuses as well as parliamentary networks on HIV/AIDS.
11. Sign up to a creed of best practice for combating HIV/AIDS and countering stigmatization and discrimination.

(Source: *The Role of Parliamentarians in Combating the HIV/AIDS Pandemic, Commonwealth Parliamentary Association, 2005*)
Unit 4: Questions

Please answer each of the following questions. If you are taking this course in a group you may then meet to discuss your answers.

1. Why is parliamentary leadership on HIV/AIDS important? Provide examples that differentiate parliamentary leadership from government leadership in response to the pandemic.

2. How is your parliament currently contributing to the national response to HIV/AIDS?

3. Using your country as an example, what are the key challenges and obstacles that limit how MPs engage on HIV/AIDS issues?

4. Identify some measures that could be undertaken to strengthen parliamentary leadership in response to HIV/AIDS.

Selected Bibliography:

The Role of Parliamentarians in Combating the HIV/AIDS Pandemic, Commonwealth Parliamentary Association, 2005

Taking Action Against HIV – A handbook for parliamentarians, IPU/UNAIDS/UNDP, 2007


HIV/AIDS and Democratic Governance in South Africa, IDASA, 2004

The Political Cost of AIDS in Africa, IDASA, 2008

Governance of HIV/AIDS Responses: Issues and Outlook, UNDP, 2006

Internet resources:


www.appg-aids.org.uk
www.awepa.org/
www.pfaindia.in
www.policyproject.com/pubs/toolkit.cfm
www.unaids.org

**Suggestions for further reading:**


*Together We Can – Leadership in a world of AIDS*, UNAIDS, 2001