

Raising the Profile of HIV and AIDS in Your Parliament



Inter-Parliamentary Union (IPU)



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This guide is intended as a practical tool for parliamentarians who wish to organize themselves into cross-party groups and step up to the challenge that HIV presents. It is also designed for the civil society organizations that wish to work with them.

Cover photo:
Anti-retroviral drugs
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1 | Why is it important for parliamentarians to work in groups and with civil society on HIV?

HIV continues to be one of the world's most devastating diseases. Thirty-four million people live with HIV worldwide and AIDS claims at least a million lives in Sub-Saharan Africa each year.¹ Fewer than half of those living with HIV in low and middle income countries have access to the drugs they need to manage the virus.² Meanwhile, in wealthy countries, whilst access to treatment is generally good, undiagnosed HIV and HIV-related stigma remain serious problems.

According to the UNAIDS 2011 World AIDS Day Report, a more strategic approach to tackling HIV could transform the global HIV picture. Such an approach – which will require both political commitment and a conducive legal environment – could avert at least 12.2 million new HIV infections and prevent 7.4 million AIDS-related deaths.³ Political leadership will be key to achieving these goals.

At the 2011 UN General Assembly High Level Meeting on AIDS, political leaders resolved to intensify their efforts to 'eliminate HIV and AIDS'.⁴ At the same meeting, leaders:

- committed to 'create enabling legal, social and policy frameworks in each national context in order to eliminate stigma, discrimination and violence related to HIV and promote access to HIV prevention, treatment, care and support.' They also committed to 'review, as appropriate, laws and policies that adversely affect the successful, effective and equitable delivery of HIV prevention, treatment, care and support programmes.'

¹ UNAIDS World AIDS Day Report 2011 "Faster.Smarter.Better", p7.

² UNAIDS World AIDS Day Report 2011 "Faster.Smarter.Better", p19.

³ UNAIDS World AIDS Day Report 2011 "Faster.Smarter.Better", p29.

⁴ U.N. General Assembly, 65th Session (2011) ["Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS" A/65/L.77]
http://www.un.org/ga/search/view_doc.asp?symbol=A/65/L.77

- committed to 'continue engaging people living with and affected by HIV in decision making; planning, implementing and evaluating the response, and to partner with local leaders and civil society.'
- committed to 'working towards closing the global HIV and AIDS resource gap by 2015, currently estimated by the Joint United Nations Programme on HIV/AIDS to be \$6 billion annually.'
- committed 'to breaking the upward trajectory of costs through the efficient utilization of resources.'

Delivering these commitments will require parliamentarians to exercise their legislative, representative, resource mobilisation and oversight roles respectively.

“Parliamentarians can help the public understand that, even though HIV promotes prejudices and misconceptions because of its relationship to blood, sex, drug use, sickness and other often sensitive subjects, it can be effectively prevented and treated like other diseases, if these prejudices and misconceptions are overcome.”

– IPU Handbook for Parliamentarians:
Taking Action Against HIV and AIDS.

Many studies have highlighted the potential of national legislatures to improve the HIV response.^{5,6,7} However, research also suggests that parliaments are 'behind the curve' and could do more to demonstrate political leadership and properly execute their representative, legislative and oversight functions on the issue.^{8,9,10} As economic belts are tightened all over the world, it is more important than ever that parliamentarians fulfil these roles, ensuring value for money in HIV and AIDS expenditure, that the rights of people living with HIV are upheld and that comprehensive prevention plans are in place.

5 IPU "Taking Action Against HIV and AIDS: Handbook for Parliamentarians" 2007.
6 The All Party Parliamentary Group on AIDS "The Treatment Timebomb" July 2009.
<http://test.aidsportal.org/atomicDocuments/AIDSPortalDocuments/APPGTimebomb091.pdf>
7 Glassman, A. "How Parliamentarians can Help Ensure Accountability for Spending on HIV/AIDS and Reproductive Health" 2007, World Bank Institute, Washington DC.



Participants at the National Convention of Parliamentarians, Legislators, Zila Parishad Chairpersons & Mayors on HIV/AIDS in New Delhi in July 2011, an event organized by the Forum of Parliamentarians on HIV/AIDS in India. The Chief of the National Planning Commission used the Convention to make a ground-breaking commitment to protect the Indian HIV and AIDS programme from the effects of the global financial crisis by guaranteeing domestic financial support.

© The Forum of Parliamentarians on HIV and AIDS (FPA)

Parliamentarians can make a difference

Parliamentarians can use their representative, leadership, legislative, resource mobilising and oversight roles to improve their country's response to HIV and AIDS.

- **Representation and engagement with civil society.** Most MPs have at least some constituents living with HIV, whose needs they can represent at a national level. In addition, they can give a voice to key populations¹¹, and organized groups, such as HIV charities or HIV support groups, which may otherwise be neglected at a national level.

8 Ibid.
9 Searle, A. "African legislatures and HIV AIDS: An exploratory analysis.", 2011, Democracy in Africa Research Unit, University of Cape Town, South Africa, P71.
10 The AIDS 2031 Consortium, "AIDS: Taking a long term view: The AIDS 2031 Consortium." 2011. Pearson Education Inc. FT Press. USA.
<http://www.ftpress.com/store/product.aspx?isbn=0132172593>
11 UNAIDS defines 'key populations' as "those most likely to be exposed to HIV or to transmit it ... [and whose] engagement is critical to a successful HIV response." Key populations usually include men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and the HIV-negative partners of people living with HIV.

Advice for Parliamentarians: Legislating with Care

“Before rushing to legislate ... we should give careful consideration to the fact that passing HIV-specific criminal legislation can:

- further stigmatize persons living with HIV;
- provide a disincentive to HIV testing;
- create a false sense of security among people who are HIV-negative; and,
- rather than assisting women by protecting them against HIV infection, impose on them an additional burden and risk of violence or discrimination.

In addition, there is no evidence that criminal laws specific to HIV transmission will make any significant impact on the spread of HIV or on halting the epidemic. Therefore, priority must be given to increasing access to comprehensive and evidence-informed prevention methods in the fight against HIV/AIDS.”

Extract from the Final Conclusions, The First Global Parliamentary Meeting on HIV/AIDS, Manila, Philippines, 28-30 November 2007

- **Leadership.** Parliamentarians can use their positions and access to mass media platforms to promote respect for people living with HIV and to promote well-informed public debate on the best ways of tackling the virus. They can lead by example, for instance, by taking HIV tests and by avoiding and speaking out against stigma, discrimination, violence against women, gender inequality and harmful cultural practices – all of which can increase vulnerability to HIV.
- **Legislation.** Parliamentarians can design and amend laws to ensure the best policies are in place to support people living with HIV and to prevent new infections. Some legislation can be counter-productive in the fight against HIV and parliamentarians need to use this role with the utmost care and consideration for human rights and effective responses to HIV.
- **Resource mobilisation.** Parliamentarians can have an input into government spending decisions relevant to the domestic and international HIV response, ensuring that adequate resources go to health and to HIV.
- **Oversight.** Parliamentarians can use their oversight role to monitor the effectiveness of government expenditure and delivery of HIV-related commitments.

Work together and achieve more

Parliamentarians who wish to play a part in tackling HIV are likely to find they are more effective when they work in groups and build links with networks outside parliament. Cross-party groups working on HIV can be a particularly effective vehicle for action and results because they provide:

- **Credibility.** Numerous political voices calling in unison for change across political divides are more likely to be heard and taken seriously than lone advocates, important though such individuals are.
- **Longevity.** Cross-party working enables legislation and leadership that survives political change. Secretariats to cross-party groups can provide important continuity as elected leaders come and go.
- **Expertise.** Strong partnerships with civil society and those responsible for service delivery can bring expertise into parliamentary discussions and can facilitate evidence-informed policymaking and a better understanding of the lived realities of people living with HIV.
- **Capacity.** Organized parliamentary groups may be able to attract resources in terms of funds and staffing, that individuals could not. Such resources increase parliamentarians’ capacity to engage in legislation, representation, advocacy and oversight.



HIV/AIDS related stigma is still a major obstacle in the fight against the disease

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2 | Different models of parliamentary HIV and AIDS committees, groups and caucuses

There are many cross-party committees, groups and caucuses working on HIV and AIDS around the world and each is slightly different from the other. However, for the purposes of this guide, they fall into two main categories, official and unofficial committees. An official committee is defined here as a committee which is allocated parliamentary time and staffed by clerks who are paid by the parliament. All other committees, caucuses and groups fall under the 'unofficial committee' category.

Within official and unofficial categories there are several models. Official committees, for example, may be sub-committees of a broad subject committee, such as a health committee and they may or may not be able to draft new bills. Unofficial committees may have some official advantages, for example, they may have a statutory consultative relationship with the national AIDS programme (this is the case in India), or they may be able to use parliamentary headed paper and use offices within the parliamentary estate (this is the case in the UK).

This brief will showcase four successful committees that deal with issues related to HIV and AIDS - two unofficial and two official:

- **UK:** Unofficial, active group (inside parliament)
- **Tanzania:** Official parliamentary standing committee (inside parliament)
- **India:** Unofficial, active caucus (outside parliament)
- **Switzerland:** Official parliamentary committee (inside parliament).

The advantages and disadvantages of official and unofficial committees

Type of Committee	Advantages	Disadvantages
Official	<p>Funded by parliament, served by parliamentary staff and located on parliamentary premises.</p> <p>Has statutory powers, such as the power to summon witnesses.</p> <p>Recommendations must be considered by government.</p> <p>High status.</p> <p>Members can develop a new interest in HIV.</p>	<p>Members are appointed by parties, rather than self-appointed and therefore may not have a personal interest in the subject or develop one.</p> <p>Voting can be ‘whipped’ leading to political rather than evidence-informed consensus decision-making.</p> <p>Official committees can be cumbersome to set up and costly to run. Therefore, in lower prevalence countries a permanent committee may not be deemed suitable.</p>
Unofficial	<p>Members are self-appointed, guaranteeing their interest.</p> <p>Relatively easy to set up – most parliaments have provisions for unofficial caucuses.</p> <p>Can respond quickly to emerging advocacy and action needs.</p> <p>Tend to have stronger links with civil society, since partnerships are required for funding and research.</p> <p>Can be more independent of government than a typical official committee in which the government ensures it has a voting majority.</p>	<p>Fundraising usually required to pay for staff.</p> <p>Work required to organize office space for staff and employment contracts (since staff will not be employees of parliament).</p> <p>Meetings are not part of the official (whipped) parliamentary timetable and so can be neglected by parliamentarians in favour of official business.</p> <p>Takes time to establish a positive reputation inside and outside of parliament because it lacks the status of an official committee.</p> <p>No power to summon witnesses.</p>

What type of committee is right for my country?

It may be that you have an active parliamentary standing committee on health or social welfare that treats HIV as one of its priorities, in which case setting up a separate formal committee on HIV could be an unnecessary duplication.

However, HIV is not simply a health and social welfare issue but an issue which touches on human rights, justice, trade policy and education amongst other areas. Even if there is an active health committee, it may be useful to constitute a committee of parliamentarians who wish to develop particular policy expertise on HIV and to concentrate on and coordinate lobbying across government departments.

This is one of the reasons that South Africa decided to set up a full official committee to focus on HIV and AIDS, despite already having an AIDS subcommittee under the Health Committee. At the announcement of the new AIDS Committee in South Africa, the Health Committee Chairperson, Monwabisi Goqwana MP, said the establishment of the AIDS committee was an indication by the government that it was serious in the fight against the disease.

“HIV/AIDS is not a health issue, it’s a cross-cutting disease (affecting) all departments,” he said, “Since HIV is a cross-cutting disease it needs to be handled by a committee,” Goqwana added.¹²

However, setting up an official committee can be a cumbersome process. Equally, in countries with concentrated epidemics, parliamentarians may feel it is not necessary to spend significant parliamentary time and resources on an HIV-specific official committee.

An unofficial group of parliamentarians is an alternative to setting up a formal, resource intensive, parliamentary committee. The case studies of UK and India in this guide indicate that such informal groups can be highly effective. The two models have their advantages and disadvantages, but both can have a positive impact on HIV policy.

¹² Reported in <http://www.hst.org.za/news/hivaids-committee-shows-serious-attitude> and The New Age newspaper 21st June 2011
http://www.thenewage.co.za/21174-1007-53-HIV_Aids_committee_shows_serious_attitude



State Conference for HIV/AIDS peer educators in India, most of whom are HIV positive themselves.
© The Global Fund/John Rae

3 | What are the common parliamentary tools that can be used?

Official HIV and AIDS committees and unofficial committees may have slightly different parliamentary tools at their disposal. Nonetheless, there are many activities that parliamentarians involved with either type of committee can undertake.

As a parliamentarian you can:

- Review existing HIV-relevant legislation to establish if it meets international and national human rights commitments, national constitutional obligations and UNAIDS/WHO best practise recommendations. The IPU Handbook for Parliamentarians “Taking Action Against HIV and AIDS” has a section on ‘shaping supportive laws and policies.’
- Review draft bills and respond to government consultations on new HIV strategy or legislation.
- Meet and correspond with outside institutions and experts, including people living with HIV, key populations and those involved with service provision.
- Encourage your committee or the most relevant official committees to run official inquiries on HIV.

“I took an HIV test this World AIDS Day to help raise the profile of the campaign to ensure people at risk get tested. Early diagnosis really can help to save people’s lives.”

– Simon Kirby MP, Vice Chair, APPG on HIV& AIDS, UK.



Simon Kirby
© UK All-Party Group on HIV and AIDS

Advice for HIV and AIDS Committee Staffers and Civil Society Organizations Working with MPs

Civil society organizations can ask parliamentarians to use the following routine parliamentary tools in support of HIV-friendly policies:

- Tabling amendments to bills
- Tabling private members' bills
- Meeting and lobbying ministers for health, international development and those with other relevant portfolios
- Tabling parliamentary questions
- Tabling parliamentary motions
- Speaking in parliamentary debates
- Participating in detailed inquiries (as a civil society organization you may be able to give evidence yourself in any parliamentary inquiries on HIV. Your MP contact will explain to you how to do this).

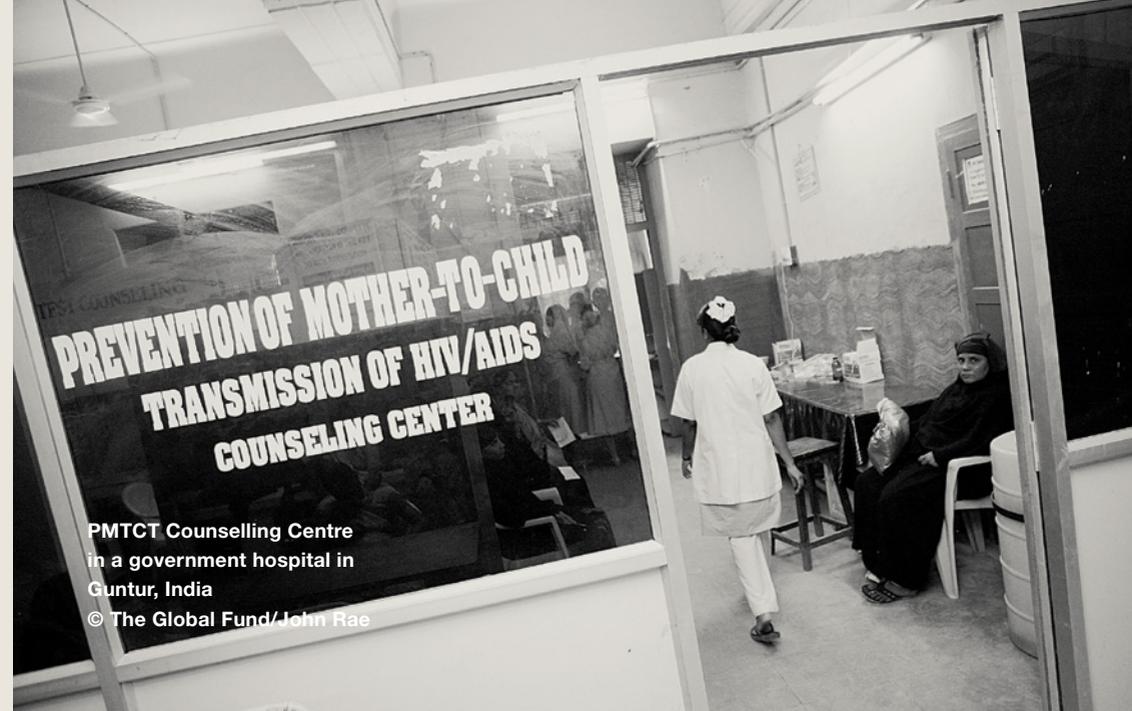
Taking the initiative

There is a delicate balance between ensuring that parliamentarians feel some sense of ownership of a committee and ensuring the committee achieves results. Parliamentarians are very busy, so you need to make life easy for them. Suggest ideas for activities, and if they agree, do most of the work. Bear in mind that organizing events can be a distraction from more useful forms of advocacy. Anyone can attend a meeting but few people can table an amendment to a bill or set up a meeting with a minister. These less public forms of activity can often be the most effective.

Do not be shy to draft letters, legislative amendments and parliamentary questions (if you know how). In almost every activity, you will do most of the preparatory work and the parliamentarian will do the final part.

If you have a large membership of parliamentarians, you cannot consult every member on every activity and policy position, so sometimes you will have to risk going ahead with the agreement of just a few members. One option is to write a disclaimer clarifying that a particular policy position represents the views of the committee's executive officers (President, Vice President etc), but not necessarily every member.

Help parliamentarians to get credit for what they do, for example, by providing press releases they can use in their local papers. It will make them more likely to help again! However, some more controversial issues may be better dealt with quietly.



- Organize and chair events, including events to bring the voices of people living with HIV to policy makers and to improve parliamentary understanding of HIV-related policy challenges.
- Advocate for sufficient government funding for an effective HIV and AIDS response.
- Monitor government expenditure and implementation of national and international commitments such as the Abuja Declaration, which many governments signed in 2001, committing themselves to allocating a target of 15% of their annual budgets to health.
- Promote awareness on the importance of testing and treating people who live with HIV with respect, in your constituency and nationally.



Ntompizandile Mati,
a migrant worker in South
Africa, thin and in poor health
before receiving Anti-Retro
Viral (ARV) treatment
© Larry Towell/ Magnum
Photos for the Global Fund

4 | Key practical considerations for parliamentarians and civil society organizations wishing to set up a cross-party committee

Party balance

A cross-party committee on HIV should have a structure of Presidents/ Chairs and Vice-Presidents/Vice-Chairs that ensures that each major political party is represented. In an official committee this party balance is likely to be automatic, as the parties will nominate members. However, in an unofficial committee the members and staffers will need to recruit interested members from across parties. This is necessary for the legitimacy of the group, its longevity and the preservation of its achievements. Some parliaments have specific requirements for numbers of parliamentarians from each party before they allow groups to be registered.

Advice for HIV and AIDS Committee Staffers and Civil Society Organizations Working with MPs

Cross-party involvement should be more than names on a list. It is important that staff working for the committee build relationships with MPs from all parties and have at least one strong advocate in each. When designing campaigns, staff should also bear in mind that a victory today may be reversed tomorrow if the opposition does not agree with it. Therefore, opposition ministers need to be lobbied too.

Leadership

A good leader (Chair or President) may be the single most important factor determining the effectiveness of your committee. The Chair should be passionate about the subject area, willing to communicate with groups outside parliament including key populations, motivated to make a difference and able to dedicate time to committee activities.

The Chair should be supported by other parliamentary 'executive officers' who are willing to help share the work and represent the group



Ntompizandile Mati,
four months after beginning
ARV treatment, playing with
her child.

© Larry Towell/Magnum
Photos for the Global Fund

in the absence of the Chair. It is sensible to ensure you have a balance of political parties represented between the Chair and the officers.

Staffing

A cross-party parliamentary committee will benefit from having staff. In the case of unofficial committees, this is likely to be the single biggest expenditure item. A single skilled staff member, with a good knowledge of how parliament works, can be enough to run a group – though some groups have more. Staff should be willing and able to work with parliamentarians from all parties and be sensitive to their differences.

An important consideration in unofficial committees is the issue of who the staff member/s work for and are directed by. This may or may not be the same as the source of funding for the group. For example, in the case of the UK's All Party Parliamentary Group on HIV & AIDS, funding comes from a number of different sources directly to the Committee, and then salary money is passed on to an independent civil society organization, which administers the salary. In other cases, like Serbia, staffing is managed by a civil society organization outside parliament.

Whenever salaries are paid or administered by outside bodies, care needs to be taken to ensure that there is clarity about who the staff member is accountable to – the parliamentarians or the funders/administrators of the position.

Location

Where your committee has its secretariat is an important consideration. It is good for committee staffers to be on the parliamentary estate if possible because it:

- Provides lots of *ad hoc* opportunities for meeting supportive parliamentarians.
- Makes it easier to spot political opportunities and avoid mistakes because you hear quickly about what is going on.
- Gives an indication to outside groups that the committee and its staff are well accepted by and integrated into parliamentary systems.

Some secretariats will be based in the office of one of the parliamentary members of the committee. If working in parliament is not possible, security clearance to get into parliament and a location close to parliament is useful.

“To run this operation you need to have an anchor very close to parliament.”

– Navneet S. Tewatia, Program Coordinator,
Forum of Parliamentarians on HIV/AIDS, India.

Funding

Official parliamentary committees will be primarily funded by parliament, although some may occasionally need to raise additional funds.

Unofficial parliamentary groups will need to raise their own funds. They should be very careful about where they get their funding from. Accepting funding from the government, as an unofficial committee, may limit the committee’s ability to criticise government policy. Funding from donors may also come with expectations that the donor will have its policy positions supported over and above the positions of its civil society peers. Equally, the private sector may expect support for policy positions in exchange for funding. Any expectations of favour should be clearly dispelled.

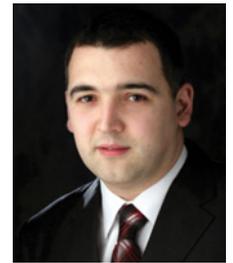
It is therefore useful if funding comes from various sources to give the group as much independence as possible. All committees that accept funds from outside parliament should have a clear policy on funding and whether funders can expect any influence over the committee’s work. If a committee chooses to accept a single-source funding model, they will have to be particularly clear on this issue.

Relationships with non-parliamentary organizations

A good committee will have strong relationship with external experts, who can support them with written and verbal research and policy advice. Experts should include people living with HIV who can ensure parliamentarians get an understanding of what it is like to live with the virus and how policies are working in practice. UNAIDS has published

“One of the priority tasks in the work of MPs involved in a cross-party Committee for HIV/AIDS and Reproductive Health is to directly communicate with people living with HIV. Involving them in different activities is a good opportunity to speak publicly about the necessity of testing, as well as to fight the stigma and isolation which they sometimes face. This is also the chance to show that there is no danger, and that it is perfectly normal to share a living or working environment with a person living with HIV. Decisive leadership, cooperation and commitment are necessary prerequisites to provide enough support for individuals, families and a community as a whole regarding this issue.”

– Dr. Nikola Lazic MP, Vice-Chair of the Serbian Parliamentary Group on HIV/AIDS and Reproductive Health.



Nikola Lazic
© Nikola Lazic

a set of guidelines against which it measures its own relationship with civil society organizations, key populations and people living with HIV, which may be a useful reference for parliamentary committees.¹³ Committees should also have a close working relationship with National AIDS Commissions/Councils, Departments of Health and other relevant government departments, which can bring important practical experience and data to policy-making and may be able to advise on key national legislative challenges.

Expert views should also be sought from academics, clinicians and service providers who can speak from experience about the challenges of reaching the population with testing, treatment, care, support and prevention services.

¹³ “UNAIDS guidance for partnerships with civil society, including people living with HIV and key populations” http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236_guidance_partnership_civilsociety_en.pdf, UNAIDS Guidance document 2011.

Sensitive issues

If MPs are reluctant to get involved controversial issues, such as injecting drug use, involve them on other things first. Few can object to calls to help prevent babies from becoming infected with HIV. Over time their views may change and the contact with them will be useful. Putting MPs into direct contact with people from key populations at higher risk of HIV exposure can also help humanise the issue and persuade parliamentarians of the need to support all people at risk of contracting HIV.

Whilst strong relationships with NGOs are crucial, committees need to be wary that they do not simply become platforms for individual NGOs/civil society organizations who wish to increase their status within parliament.

Tackling socially taboo issues

If your committee is not working on some socially taboo issues, it is probably ignoring an important component of the national epidemic and therefore limiting its own effectiveness.

At the First Global Parliamentary Meeting on HIV and AIDS held in Manila in 2007, parliamentarians concluded that certain groups of people, including men who have sex with men, people who use drugs, sex workers, prisoners, refugees, internally displaced persons and people with disabilities are neglected in the AIDS response. They noted that “the resources devoted to their HIV prevention, treatment and care are not proportional to the HIV prevalence” and that this was reducing the effectiveness of the HIV and AIDS response.¹⁴

Parliamentarians can lobby to ensure that these groups have access to HIV prevention, treatment care and support and are included in national HIV plans. They can also consider whether their country has laws, such as those criminalizing consensual homosexual activity between adults, that hinder the HIV and AIDS response, and make it harder for certain groups to access essential services.

¹⁴ Final conclusions, The First Global Parliamentary Meeting on HIV/AIDS, Manila, Philippines, 28-30 November 2007, <http://www.ipu.org/splz-e/h aids07.htm>

Integrating HIV with other issues

If your parliament already has a formal HIV committee, it is important that the other committees do not feel absolved of including HIV in their work. The HIV committee can help highlight relevant areas for attention by other official committees. Labour and Social Welfare Committees, for example, may be responsible for overseeing policies designed to improve access to the workplace for those with disabilities – such oversight should include workplace HIV policy; Justice Committees may look into issues of criminalization and Audit Committees may work on HIV spending.

Whether or not your committee is official or unofficial, it will also be important to consider how HIV inter-relates with other diseases, such as tuberculosis, and with other health care requirements, such as reproductive health. If these other subject areas have their own official or unofficial committees, it is often useful to work jointly. Putting HIV into context will enable more effective policy making.

“I ask you to lead the movement to ensure that by 2015 all children will be born free of HIV and their mothers will be kept alive. We have the technology and know-how to make this happen. We need your political leadership to transform this achievable goal into reality.”

– Michel Sidibé, Executive Director UNAIDS, speaking to parliamentarians at The National Convention on HIV & AIDS, India, July 2011. The Convention was organized by India’s Forum of Parliamentarians on HIV/AIDS.

Outside support

The IPU has an Advisory Group on HIV/AIDS and has an HIV policy specialist staff member. It can provide further advice on setting up committees. The SADC parliamentary forum has a standing committee on HIV/AIDS which aims to strengthen the role of members of parliament in the fight against AIDS. It has seconded staff from SADC to member parliaments to support work on HIV.

Case Study: All Party Parliamentary Group on HIV and AIDS, United Kingdom

Established: 1986

Official or unofficial committee:

Unofficial. However, it is recognised by parliament and registered as one of Westminster's many All Party Parliamentary Groups (APPGs). It works closely with official committees, such as the International Development Select Committee, and a Vice Chair of the group was able to set up a temporary official Committee for a hearing on HIV in the House of Lords.

Staffing, funding and location:

The group receives funding from a mix of private sector (mostly pharmaceutical) and not for profit donors. It has single staff member, based in the parliamentary office of the group's Chair. An external HIV charity administers the staff salary on behalf of the group. Management responsibility lies with the group's Chair and Vice-Chairs.

The main functions of the committee:

- To ensure that UK laws and policies deliver for people living with HIV and are respectful of their human rights.
- To promote public health.
- To advocate for government resources to tackle HIV at home and abroad.

Structure and membership:

The group has a Chair and six Vice Chairs who come from a mix of political parties and from both Houses of Parliament. There are about 120 members, but the active group of MPs is smaller at around 40.

Relationship with government:

The group is respected as a source of expertise on HIV in parliament. The Chair and Vice Chairs are able to secure formal and informal meetings with ministers and civil servants across all relevant Departments to discuss issues of concern from health and welfare in the UK, to international development.

Relationship with people living with HIV:

The group supports organizations of people living with HIV and key populations to have access to parliament and raise their concerns with government. It includes them in all its research and ensures people living with HIV are included on speakers' panels at all speaking events. It recently arranged for 20 young people living with and affected by HIV to meet with their local MPs in Parliament.

"Many in the UK tend to think of HIV as something that happens to someone else, somewhere else. But the reality is that in the UK the number of people living with the virus has trebled over the last decade and those people need to be supported. The APPG is fighting for good policies for them and for investment in prevention programmes to slow the number of new infections."

– Pamela Nash MP, Chair, The All Party Parliamentary Group on HIV&AIDS.



Pamela Nash
© Pamela Nash

Recent notable achievements of the group:

A quarter of all HIV infections in the UK are undiagnosed. In order to tackle this, the group has recently ensured that prompt diagnosis of HIV is an indicator against which health authorities across the country will be measured, creating a strong incentive for health authorities to invest in HIV testing campaigns.

The APPG has finally won a long campaign to end charging for HIV treatment for certain categories of migrants in the UK. The charges were discouraging some people from testing and seeking treatment and were often levied against people who had little or no means to pay. This change will better protect public health as well as the health of the individuals concerned.

Case Study: The Committee for Social Security and Health, The Council of States, Switzerland

Long established as part of the Swiss Council of States

Official or unofficial committee:

Official. It has the power to call witnesses, including ministers. The Committee is funded and staffed by parliament and based in the parliamentary buildings. There is an equivalent committee in the National Council – the other Chamber in Switzerland’s legislature.

The main functions of the committee:

The Committee is mandated to cover a wide range of social and health issues, of which HIV and AIDS are just part. The wide scope of the Committee enables Members to look at HIV holistically from both a health and a social perspective.

“The committees have always been very supportive of the government’s rather explicit public information campaigns, even if certain religious groups asked for a reduction of public spending for such campaigns. Without such political support for explicit, non-discriminate messages we would not have had successful health campaigns in Switzerland.”

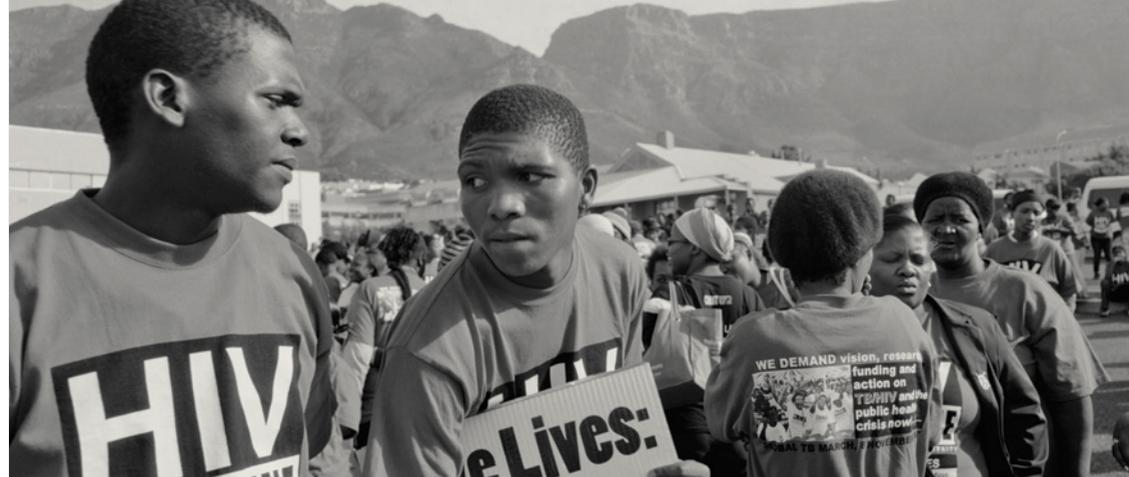
– Dr. Felix Gutzwiller, Physician, MP, Member of the Committee for Social Security and Health, Council of States, and Member of the IPU Advisory Group on HIV/AIDS.



Felix Gutzwiller
© Felix Gutzwiller

Structure and membership:

The Committee has a President and twelve members. Membership reflects party balance and members are appointed through the executive committee of both houses of parliament. Voting often reflects party lines, however, members sometimes vote across party lines on issues of ethical or societal concern. Members of the committee – who might not have wished to sit on an HIV specific group – have built up an interest and some policy expertise on HIV.



Access to Life is a collaboration between the Global Fund to Fight AIDS, Tuberculosis and Malaria and Magnum Photos, to document individuals benefitting from ARV treatment around the world.

© Larry Towell/Magnum Photos for the Global Fund

Relationship with government:

The Committee works with the government through the Federal Office of Public Health and will be discussing the Federal Office’s new Strategic Plan on HIV and AIDS in the near future.

Relationship with people living with HIV and marginalized groups:

The committee arranges contact visits and invites representatives of different social groups – usually civil society representatives – to give evidence to inquiries.

Recent notable achievements of the group:

- Improved legislative oversight on HIV and AIDS.
- Improved labour laws and protection against discrimination in the workplace for people living with HIV.
- Strong and effective public information campaigns on HIV in the face of some resistance from conservative religious groups.

Case Study: Parliamentary Standing Committee on HIV/AIDS, Tanzania

Established: 2008

Official or unofficial committee:

Official. It has the power to call witnesses, including ministers. The Committee is funded and staffed by the parliament. The Committee also has a close relationship with an unofficial group, The Tanzanian Parliamentary AIDS Coalition (TAPAC). All members of the official Committee are also members of TAPAC, which boasts over 200 parliamentary members. TAPAC was established in 2001 and helped bring about the establishment of the official Committee.

Staffing, funding and location:

The Committee has three staff; two Committee Clerks and a Parliamentary Researcher who are employees of parliament and work inside parliament.

The main functions of the committee:

- Coordinate HIV and AIDS activities of the Office of the National Assembly (Parliament).
- Examine and make recommendations on government plans and policies on HIV and AIDS.
- Scrutinize the implementation of plans and policies on HIV and AIDS.

Structure and membership:

The Committee has a Chairperson and 22 other members. It represents all political parties in parliament. Despite being an official committee, members do not tend to vote along party lines.

Relationship with government:

The Committee works with the government through the ministries, the Tanzania Commission for AIDS (TACAIDS) and the Tanzania National Coordinating Mechanism (TNCM), which both fall under the Prime Minister's Office, and the National AIDS Control Programme, which is under the Ministry of Health.

"Tanzania has both an official standing committee and an informal parliamentary caucus on HIV and AIDS. The official committee enables us to ensure HIV issues are on the government agenda, since the government is obliged to respond to committee recommendations.

The unofficial committee enables us to foster improved understanding of HIV among a much wider group of around 250 parliamentarians, so that when HIV issues come to the floor of the House, colleagues can debate in an informed, unprejudiced fashion; they are also better equipped to deal with HIV issues in their constituencies."

– **Hon Lediana Mafuru Mng'ong'o, MP, Chair of Tanzanian Parliamentarians AID Coalition and the Parliamentary Standing Committee on HIV/AIDS, Member of IPU Advisory Group on HIV/AIDS.**



Hon Lediana Mafuru Mng'ong'o
© The Tanzanian Parliamentary AIDS Coalition

Relationship with people living with HIV:

The Committee has an excellent working relationship with organizations of people living with HIV, such as The Network of Women Living with HIV (NETWO+), The National Council for People Living with HIV and AIDS (NACOPHA), the National Network of Youth Living with HIV/AIDS and others.

Recent notable achievements of the committee:

- A rise in the level of debate and analysis in parliament and legislative oversight on HIV and AIDS.
- Improved access to national decision makers for community-based organizations and people living with HIV.
- The Committee has submitted a recommendation to the government that clauses in the HIV/AIDS Prevention and Control Act 2008, which criminalize the transmission of HIV and punish it with a jail sentence of up to 10 years, should be removed. The committee has already managed to reduce the length of the prison sentence for transmission of HIV from a proposed life sentence.

Case study: The Forum of Parliamentarians on HIV/AIDS (FPA), India

Established 2002 and formally registered as a not for profit organization in 2009

Official or unofficial committee:

Unofficial. However, it is officially recognised by government as an advisory body to the 'National Council on AIDS', a high level council chaired by the Prime Minister.

Staffing, funding and location:

The FPA has a Programme Coordinator, an assistant and two support staff. It is funded by UNAIDS India, and benefits from low-cost basic office space, arranged by a supportive MP close to parliament.

The main functions of the committee:

- To sensitise elected representatives about HIV and AIDS and through them, raise awareness among the public.
- To influence and encourage policy makers and stakeholders to formulate balanced legislation and policies aimed at effective prevention of HIV infection.
- To call on the government to provide care, support, treatment and rehabilitation of people affected by and infected with HIV and to empower them at all levels to become full partners in development.

Structure and membership:

The FPA has a Core Group that consists of 64 individuals from the Upper and Lower Houses, including current and former MPs and Senators, and is balanced by geography, party and by gender. There is at least one member from every state of India. The Core Group meets four times a year. In addition to the core membership, the FPA has a diverse wider membership of MPs and former MPs from all the political parties.

Relationship with government:

The government recognises and respects the FPA – for example by including the President and the Secretary on governmental delegations to UN High Level meetings on AIDS. The FPA has a strong relationship with the National AIDS Control Organization, NACO.

Relationship with people living with HIV:

The FPA deals predominantly with the National AIDS Control Programme and UNAIDS, which include people living with HIV in their decision making. It welcomes people living with HIV as speakers at events, ensuring their voices are heard.

“We at the Forum are committed to taking the issue of HIV/AIDS to the masses by engaging with elected representatives up to the village level and creating a space for informed deliberations on the issue which enables us to contribute more effectively to the national HIV/AIDS response.”

– Oscar Fernandes, MP & President of the Forum of Parliamentarians on HIV/AIDS.



Oscar Fernandes
© The Forum of Parliamentarians on HIV and AIDS (FPA)

Recent notable achievements of the group:

The FPA organized a National Convention in 2011, attended by the Prime Minister and 850 officials and representatives, at which the Chief of the Planning Commission committed to protect the Indian HIV and AIDS programme from the effects of the global financial crisis by guaranteeing domestic financial support.

The FPA has raised the profile of the Free Trade Agreement between India and the EU which may limit India's ability to produce affordable HIV medicines. The Prime Minister has now promised not to sign any part of an agreement that undermines India's access to medicines.

In a separate success, the FPA also clarified a confusion whereby the Ministries of Health and Home Affairs ended travel restrictions to India for people living with HIV, but the Ministry of External Affairs continued to implement the out-dated policy. Thanks to the FPA, the Ministry of External Affairs has updated its requirements and people living with HIV can now travel to India without answering questions on their HIV status.

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This guide was written by Veronica Oakeshott, Vision Campaign Works, www.visioncampaignworks.com, with input from parliamentary groups in Tanzania, India, Switzerland, UK and Serbia, as well as those involved in parliamentary work on HIV in South Africa. Aleksandra Blagojevic, IPU Programme Officer for Development, provided editorial advice and support.

This guide provides practical advice for parliamentarians who wish to set up cross-party groups on HIV and AIDS in their legislatures. It accompanies the IPU-UNAIDS-UNDP Handbook for Parliamentarians, Taking action against HIV and AIDS. The Handbook is a call to action for bold parliamentary leadership, and serves as a comprehensive reference volume that legislators and their staff can consult for information and guidance on a wide range of issues relating to the epidemic.

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