

# Celebrating 25 years of Engagement and Impact

*A primer on The NGO Delegation to the UNAIDS Programme Coordinating Board (PCB)*





**“The position of NGOs in the UNAIDS Programme Coordinating Board is very important for the effective inclusion of community voices in the key global policy forum for HIV and AIDS. PCB NGOs represent the perspectives of civil society, including people living with HIV, within UNAIDS policies and programming.”**

**- UNAIDS Governance Handbook**



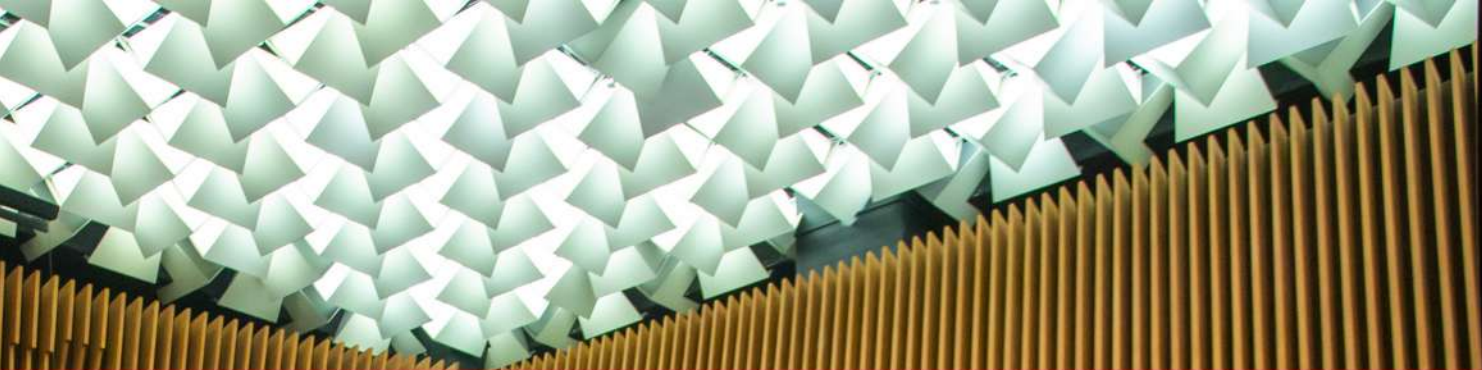


**“The NGO Delegation exists as an important part of the ecosystem of UNAIDS. Akin to climate change, the global political climate that poses a threat towards the existence and the space of the NGO Delegation as part of the PCB will only result towards the failure of UNAIDS itself. Thus, 25 years later, and now more than ever, the NGO Delegation space needs to be preserved and protected.”**

**- Jeffry Acaba,  
NGO Delegate from Asia and the Pacific (2015-2017)**

In 1995, the Programme Coordinating Board (PCB) was created to serve as the governing body of the Joint United Nations Programme on HIV/AIDS (UNAIDS). According to its Modus Operandi, the PCB acts as **“the governing body on all programmatic issues concerning policy, strategy, finance, monitoring and the evaluation of UNAIDS”**.





Currently, there are 38 members of the PCB: 22 Member States, 11 Cosponsors, and 5 Non-government Organizations (NGOs). As the first UN body to have NGOs sit in its governing board through ECOSOC resolution 1995/2, UNAIDS was clearly ahead of its time. It was also a recognition of the principle that the engagement of communities, particularly people living with HIV in the HIV response, was non-negotiable. However, as with the Cosponsors, the NGO Delegation does not have full voting rights on the PCB, but are able to participate in deliberations and propose decision points for consideration.





The NGO Delegation is composed of five (5) main Delegates and five (5) alternates that represent the geographic regions of Africa, Asia and the Pacific, Europe, Latin America and the Caribbean, and North America. Since its inclusion in the PCB in 1995 until December 2021, the NGO Delegation has had 88 organizations sit on the board, involving 111 representatives. The NGO Delegation has participated in all 49 PCB meetings to date, bringing expertise, lived experience, and collective wisdom generated from its internal discussions as well as outreach with constituencies.



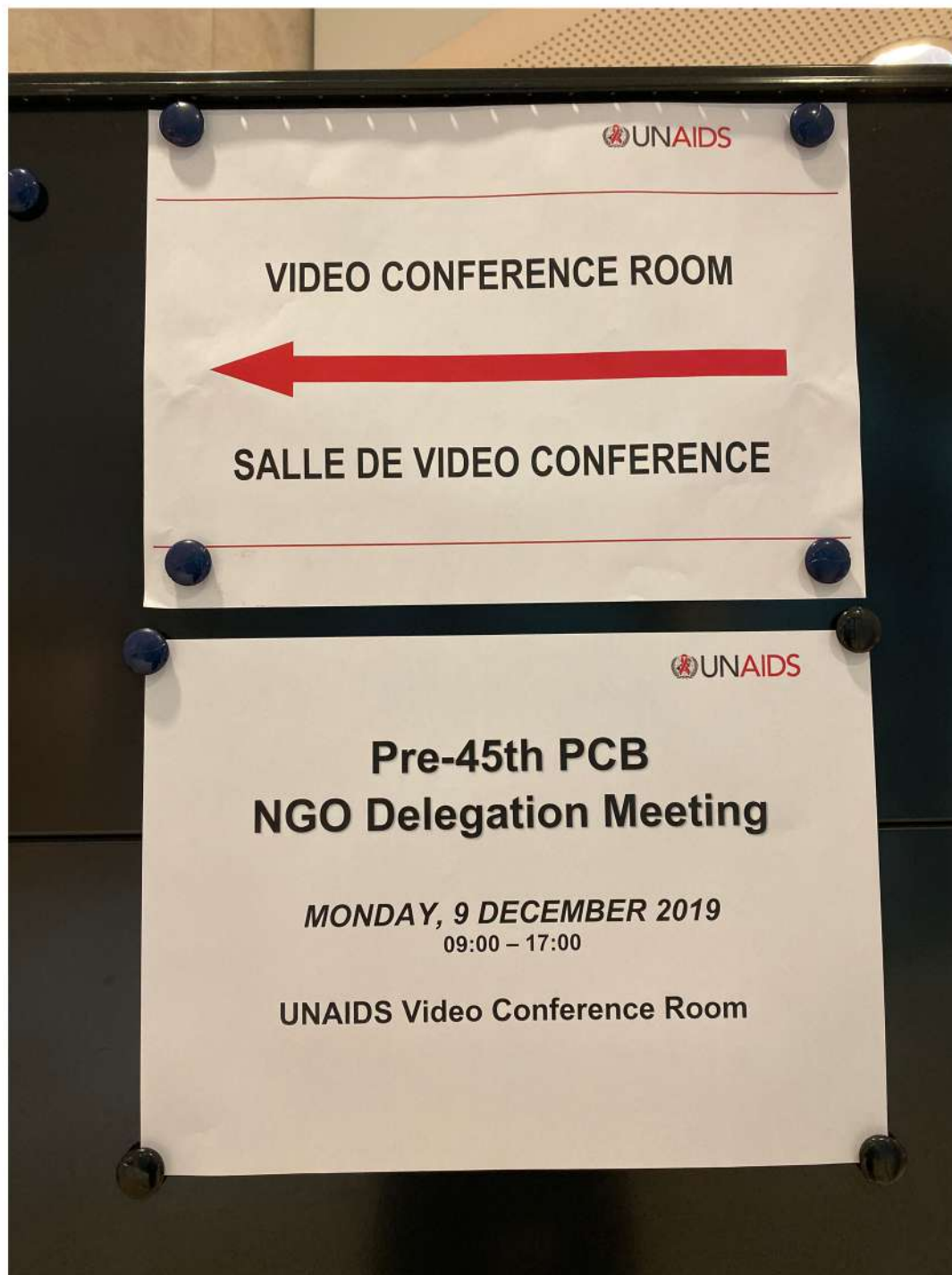


The NGO Delegation's recruitment is guided by ECOSOC resolution 1995/2, which states that 'The selection of the five nongovernmental organizations would be determined by the NGOs themselves from among those either in consultative status with ECOSOC or in relationship with one of the cosponsoring organizations or on the roster of NGOs dealing with matters pertaining to HIV/AIDS. The PCB shall formally approve the NGOs nominated.' The Delegates serve a term of two years, with a possible extension to three, based on the results of their performance assessment. The current recruitment and selection procedures are codified in the NGO Delegation's Manual of Operations.



“The participation of NGOs in the UNAIDS Coordinating Board has been a key element of UNAIDS governance since its inception in 1995. At the time, it was an unprecedented movement within organizations and United Nations programs. Even today, this is unique to the United Nations family: UNAIDS still serves as a benchmark for its inclusiveness.”

- Statement of France, on behalf of Germany, Liechtenstein and Monaco, on Agenda 1.4 (Report of the NGO Representative) at the 47th PCB Meeting, December 2020



# VISION, MISSION, and CORE PRINCIPLES



## VISION

*We envision a world where all stakeholders—people living with HIV and other key populations, civil society, governments and international bodies—meet the challenges of the global AIDS pandemic together by combining their collective competencies to generate creative, equitable, holistic, sustainable and effective policies and outcomes that lead to a world free of HIV.*



# MISSION

"To bring forward the perspectives and expertise of people living with, affected by, most at risk of, vulnerable to HIV and AIDS, as well as civil society, to ensure that UNAIDS is guided by rights-based, equitable and gender-based approaches and guarantee access to comprehensive HIV prevention, treatment, care and support for all."

**TOPICS (strategic)**

1 - <sup>throughout</sup> Sexual Harassment → culture change  
 2 - HIV in emergencies → put them on the radar → strong mechanism  
 3 - SRHR → danger → no more giving up ground  
 4 - Transition financial global-domestic  
 Effects on key population (trans?)  
 criminalized populations (how?)  
 changing punitive laws & policies  
 ↳ recommendations (how?)

**FUNDING**

5 - woman executive director  
 6 - having impact on strategy  
 7 - shrinking space  
 8 - alignment with other civil society groups  
 9 - continue to be unified → maintain diverse + engaged delegation  
 10 - UHC Universal Health Coverage  
 11 - intellectual property IT issues  
 12 - collecting data

Konlu - concrete deliverables ... Past ... 1/3

**NGO REPORT**

Step 1 → outcome goals  
 - discuss DP to get original feedback from civil society from all regions

August  
 LIC → MIC  
 template

Show that previous DPs are not implemented

Research  
 Evidence → Policy

Advocacy  
 Research → Evidence





**The Delegation's work is guided by the principles of greater involvement of people living with HIV and key population communities, human rights-based approach, non-discrimination, and gender equity.**

While the work of the NGO Delegation mainly revolves around the two PCB meetings (June and December), there are activities and tasks that are done all-year round. This includes development of the annual NGO Report; recruitment and orientation of incoming Delegates; participation in various PCB working/advisory groups or task teams; representation in the PCB Bureau (which sets the PCB meeting agenda and approves the meeting documents); and preparation and participation in the PCB meetings and the Thematic segment.



**The PCB meetings require reading of background documents, drafting and delivery of interventions, analysis of proposed decision points, internal strategizing, pre-meetings with various stakeholders, and advocacy and negotiations with Member States. In order for the NGO Delegation to undertake all of the above activities, they must also hold consultations with regional and global civil society and community constituencies to solicit inputs and provide feedback.**



# KEY CONTRIBUTIONS OF THE NGO DELEGATION



In the 25 years that the NGO Delegation has been actively involved in the UNAIDS PCB, it has influenced global HIV/AIDS policy and programming whose impacts have been felt in different parts of the world. The key contributions of the delegation are classified into six (6) areas:

## Key contributions of the NGO Delegation

1. Bringing the **face of HIV** to the PCB and persistently advocating for the priority issues of communities and civil society

2. Bringing evidence, profile, and passion to neglected and **contentious issues** for the PCB

3. Bringing a **regional perspective to the PCB**—highlighting communities and civil society issues from diverse contexts

4. Supporting the PCB to evolve the **response to HIV** and connect it to wider issues and processes

5. Contributing to the effectiveness, efficiency, and accountability of **UNAIDS governance**

6. Influencing the governance of and partnerships with **other global health institutions**



## 1. Bringing the face of HIV to the PCB and persistently advocating for the priority issues of communities and civil society



*"The NGO Delegation plays a vital role in keeping the Joint Programme on HIV and AIDS on track. It provides UNAIDS and its cosponsors with a much needed and appreciated reality check and it also speaks truth to power. Working with the NGO Delegation widened my view of the global HIV pandemic and gave me the opportunity to develop skills like international diplomacy and negotiations."*

- Alexander Pastoors, NGO Delegate for Europe (2019-2021)

For 25 years, the NGO Delegation has been composed, by majority, of people living with HIV, sex workers, people who use drugs, gay, bisexual, and other men who have sex with men, transgender people, young people, women, and people who have heightened vulnerabilities to HIV like migrant workers.





The NGO Delegation has consistently advanced meaningful engagement of communities and civil society in the HIV response and advocated for adequate financing to support and sustain community-led HIV programmes and services. At the 39th PCB meeting in December 2016, a series of adopted Decision Points (DPs) sought the commitment of Member States to:

*"Identify, address and overcome equality and cultural barriers to the effective involvement of civil society and ensure the meaningful inclusion of civil society, including people living with HIV and other key populations, young people and women at all levels of planning, as well as national and donor policy and programming frameworks to ensure full involvement, quality participation and influence in the design, implementation and evaluation of policies and programmes."* (Decision Point 5.3.a)

*"Get involved in global HIV policy, planning and programs by being part of the NGO Delegation. As a gay man living with HIV in the US, I believe in the power of the Greater Involvement of People living with HIV and our voice matters. I have been lucky to be part of moving the Global AIDS Strategy and the Political Declaration on HIV forward."*

- Andrew Spieldenner, NGO Delegate for North America (2019-2021)





In 2018, the Delegation's advocacy to adequately finance community-based and led HIV responses was reinforced when the PCB included Decision Point 10.3 encouraging Member States to commit to the following:

- Dedicate maximum available resources to fulfilling the right to the enjoyment of the highest attainable standard of health, including the 30% coverage by community-led HIV programmes and allocating 6% of HIV financing towards social enablers, as agreed in the 2016 Political Declaration on Ending AIDS;
- Review and amend relevant laws, policies, institutions and mechanisms to create and maintain a safe and enabling environment in which civil society can efficiently support the AIDS response and the achievement of the targets for, and the goal of, ending AIDS by 2030;
- Report on coverage and expenditures using the Global AIDS Monitoring and National AIDS Spending Assessment tools on an annual basis.







Among the NGO Delegation's human rights work within the PCB is ensuring that promotion of social enablers and elimination of HIV-related stigma and discrimination remain a core concern of UNAIDS and Members States. This has led to the creation of the Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination in December 2018, which "aims to accelerate global action on stigma and discrimination and close the HIV prevention, testing and treatment gaps."

*"You are the very real and very necessary voice of the people on the frontlines, shining a spotlight on what matters and what works. You have always provided a clarion call for action, reminding us all that lives are still very much on the line. And your work on the UNAIDS governing board is a shining example of the benefits of NGO inclusion."*

- Committee of Cosponsoring Organizations (CCO) HIV on Agenda 1.4 at the 47th PCB Meeting



## 2. Bringing evidence, profile, and passion to neglected and controversial issues for the PCB

*"The PCB NGO Delegation has played a critical role in bringing often challenging agendas to the PCB and charting a dynamic and brave agenda that in many occasions has played a critical role in sensitising the PCB to cutting edge issues impacting the global HIV response."*

- UNODC CS Group on Drug Use and HIV on Agenda 1.4 at the 47th PCB Meeting







The NGO Delegation ensures that HIV strategies and actions adopted by the PCB for implementation of UNAIDS and Co-sponsors are grounded on human rights and gender-based approaches, are responsive to the needs of the most vulnerable, are cognizant of societal enablers and barriers posed by stigma and discrimination, and are evidence-based. As such, the Delegation has worked tirelessly to ensure that decision-making within the PCB reflects the realities and perspectives of key and vulnerable populations, especially those issues that are considered controversial or contentious.





Despite the sensitivity and controversy surrounding some of these issues, the Delegation's diligence led to changes in HIV-related policies and priorities of the PCB and UN agencies over the years. These include persistently bringing up and naming key populations in documents and decision points; pushing for sex workers rights and comprehensive harm reduction programs for people who use drugs; challenging the PCB to address issues related to intellectual property that prevents access to life-saving ARVs and generic drugs for co-infections; advocating for health and human rights of migrants and mobile populations and people in closed settings; promoting a non-binary gender approach; addressing the issue of societal enablers and sexual and reproductive health and rights (SRHR), especially among key and vulnerable women and girls.



*"In recognizing our human rights, we must not forget that when we talk about my right to access treatment services, we are talking about my right to bodily integrity. When we speak of my right to protect myself from harm, I am exercising my right to free myself from violence and discrimination."*

- Angeline Chiwetani, NGO Delegate for Africa (2015-2016)



### 3. Bringing regional perspective to the PCB – highlighting communities and civil society issues from diverse contexts



*“The NGO Delegation brings together members from the global South and North, as well as from diverse communities and perspectives. The discussions within the Delegation can be very hard--in terms of finding a balance between regions and priorities. However, the result is an informed, shared view, which is one of the Delegation’s major strengths.”*

- Mabel Bianco, NGO Delegate for Latin America and the Caribbean (1997 and 2011–2013)







Along with the vast realities and experiences of the communities they represent, the members of the Delegation also bring with them the contexts of the countries and regions they come from, ensuring that country and region-specific issues are not left behind.

At the 43rd PCB meeting, HIV and AIDS issues in the context of migration was highlighted by the NGO report entitled "People on Move – Key to Ending AIDS", which led to landmark Decision Points that called on Members States, in partnership with communities and civil society to prioritize access to HIV prevention, treatment, care and support services for migrant workers, mobile populations and refugees, and data generation to enhance evidence on the HIV-related needs and concerns of migrant and mobile populations.





The Delegation also worked to shed light on the plight of people who use drugs in Eastern Europe and Central Asia and the human rights violations faced by this community in the Philippines. They also highlighted the need for HIV programs and services for MSM in the Middle East and North Africa region, as well as SRHR programs and services for adolescent girls and women in the Eastern and Southern Africa regions.

In order to establish synergies between regional and global HIV civil society engagement, NGO Delegates have organized consultations in their respective regions to collectively discuss and come up with joint statements and key asks to bring forward to the PCB. Some of these initiatives have been supported and funded by UNAIDS Regional Support Teams (RST), such as in Asia-Pacific.

*“HIV/AIDS in Asia Pacific is a forgotten epidemic. The NGO Delegation allows our voice to be heard. If we don’t speak about it, no one will.”*

- Aditia Taslim Lim, NGO Delegate for Asia Pacific (2018-2020)





#### 4. Supporting the PCB to evolve the response to HIV and connect it to wider issues and processes

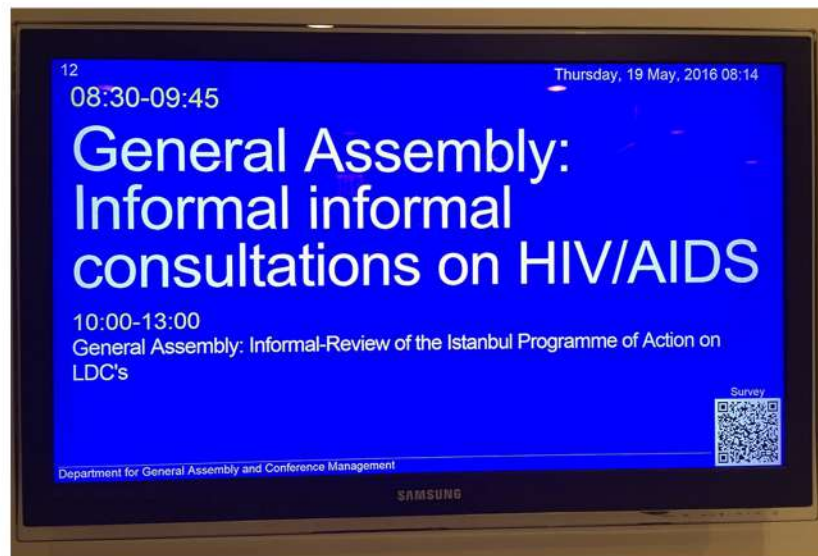
*“The Delegation’s role is to protect the relevance of HIV--by keeping its strong position within the changing world, whether of the SDGs or COVID. The work is about keeping communities, HIV and UNAIDS relevant.”*

- Sasha Volgina, NGO Delegate for Europe (2015-2016)



The NGO Delegation has worked diligently to ensure that HIV and AIDS remain at the forefront of the global development agenda by linking it to broader issues and other wider processes. It supported the PCB and UNAIDS in pushing for the HIV agenda within the Sustainable Development Goals (SDGs) by proposing to the UN General Assembly (UNGA) to convene a High Level Meeting on AIDS in 2016. The resulting Political Declaration from this meeting included the fast track agenda and the 90-90-90 targets, which then guided the direction of the international HIV response. It also recognized transgender people as key populations, which is critical in ensuring that countries establish comprehensive HIV interventions for this community. The Delegation continued its engagement with the SDGs by co-organizing events with UNAIDS in a couple of High Level Political Forums (HLPF) on sustainable Development held at the UN headquarters in New York, USA.





From time to time, the Delegation engaged in conversations and exchanges with NGO and community delegations of other global institutions such as the Global Fund to collectively advocate for the UN to ensure the inclusion of community and civil society priorities in other political declarations, that address various health agenda like Universal Health Care (UHC) and more recently, the global response to the COVID-19 pandemic.



*“Real involvement should mean that the voices of representatives of NGOs be equal to others at all levels of the various mechanisms of ending AIDS. Therefore, we would like to urge representatives of NGO delegation, Member States, and the Joint Program to formulate concrete and stronger advocacy strategies for NGOs engagement not only in the next global AIDS strategy but also in the national strategies of countries.”*

- Statement of Thailand on Agenda 1.4 at the 47th PCB Meeting



## 5. Contributing to the effectiveness, efficiency and accountability of UNAIDS governance



*"...We recognize the contributions by the NGO delegation in steering our focus on what matters most. During the years, your support has helped in the efficiency of governance within this board as well as for UNAIDS as an organization, not least in terms of UNAIDS partnership with other global health institutions such as the GFATM."*

-Statement of Austria, Iceland, Sweden, Switzerland, Norway, Finland and Denmark on Agenda 1.4 at the 47th PCB Meeting, December 2020

The NGO Delegation has influenced processes within the PCB and has substantially contributed to discussions and decisions that govern UNAIDS management and governance. Most notable of the Delegation's contributions is in the development of all the Global AIDS Strategies (formerly known as UNAIDS Strategy), as well as its accompanying document, the UNAIDS Unified Budget, Results and Accountability Framework (UBRAF), which operationalizes the strategies into concrete activities and budgets. The Delegation has advocated to ensure that community engagement, human rights, gender, and non-discrimination principles are translated into programs, are resourced, clearly monitored, and reported.

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front of implementing the Agenda 2030 agenda-and at a time when the world is  
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opment, a radical change in women's roles within UN agencies is deeply needed.

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a unique opportunity for UNAIDS to once again lead by example.

*multilateralism, evidence-based approach and*





UNAIDS and its Board also gained from the participation of the Delegation in various critical processes. For instance, the Delegation contributed in independent evaluations conducted over the years, not only by providing critical insights and recommendations, but also in ensuring that the issues of communities, particularly those of key populations are reflected in these evaluation reports. The Delegation also pushed for community engagement in these evaluation processes.





## 6. Influencing the governance of and partnerships with other global institutions

*“The NGO Delegation of the UNAIDS PCB has paved the way for community engagement in other types of health bodies. It pioneered a good practice that has now become more expected and widespread. It has shown how such meaningful engagement is very possible and how it brings solid benefits to the quality and results of the Board’s work.”*

- Laurel Sprague, Special Advisor, Community Mobilisation,  
UNAIDS Secretariat



The Global Fund took inspiration from the UNAIDS PCB in also having community and NGO delegations from developed and developing countries in its governance structure. Other global institutions like UNITAID and GAVI may have also followed the precedent set by the UNAIDS PCB’s NGO Delegation. Furthermore, other civil society mechanisms were also established in relation to the health-related goals of the SDG, such as the Civil Society Engagement Mechanism for Universal Health Care 2030 and the Global Action for Healthy Lives and Wellbeing for All are examples of how the NGO Delegation has been replicated in other settings.

These various NGO delegations work in various capacities and contexts, as well as in partnership with each other, to collectively ensure meaningful engagement of affected communities and civil society in critical decision-making at a global scale.



*"Our participation in the UNAIDS PCB has certainly set a successful precedent, which we hope will be taken up by others working on global health, and in the UN system, in support of an open and transparent United Nations governance which the world needs now."*

- Violeta Ross, NGO Delegate for Latin America and the Caribbean  
(2007-2009; 2020-2022)





# THE NGO DELEGATION OF THE FUTURE



At the 47th PCB Meeting in December 2020, the NGO Delegation submitted its annual report, “Engagement, Evidence and Impact: 25 years of the NGO Delegation to the UNAIDS PCB.” The report summed up and discussed the NGO Delegation’s impact on the PCB, specifically on the ways that it influenced and improved UNAIDS governance, management, and programming. For 25 years, the NGO Delegation has shown concrete results through the decision points that have been adopted within the PCB, as well as the enhanced frameworks and perspectives of UNAIDS, especially in relation to the issues and concerns of people living with HIV, key populations, and the HIV community at-large.



With the invaluable technical, programmatic and administrative support of the Communication and Consultation Facility (CCF), the NGO Delegation's capacity will continue to be enhanced as it forges towards a future that will see the end of AIDS, remaining steadfast in ensuring that not only are key populations and vulnerable communities heard at the highest decision-making platform of the UNAIDS, but also that the Delegation's work results in meaningful outcomes that positively impact the various HIV and AIDS responses happening on the ground.





## The Communication and Consultation Facility (CCF)



The 20th PCB meeting in June 2007 recommended “the establishment of an independent communication facility (CF) to strengthen the NGO participation and support effectiveness of NGO country-level voices in the Programme Coordinating Board policy dialogue.” In 2013, the CF was expanded to include ‘consultation’ in its functions, i.e., to facilitate constituency engagement and outreach, as a mandate of the NGO Delegation. Renamed as the Communication and Consultation Facility (CCF), it receives funding support from UNAIDS Secretariat and is independently hosted on two-year contract terms by recruited NGOs. The implementation of activities, the performance management, and overall responsibility for the achievement of deliverables belong to the Delegation.

The CCF provides independent technical and administrative support to the Delegation, subject to the scope of the contract with UNAIDS. The main tasks of the CCF have evolved over the years, to adjust to the Delegation’s work and priorities. The core functions include:

- Organising and supporting administrative aspects relating to internal and external communication of the Delegation, including managing social media engagement;
- Coordination of Delegation participation and provision of technical support in PCB meetings;
- Support for efficient functioning of the Delegation’s working groups and implementation of work plans;
- Facilitation of constituency engagement;
- Liaison with PCB Members, UNAIDS Secretariat and civil society
- Facilitation and support for accountability processes, including performance assessment, recruitment, and orientation;
- Document storage and archival work;
- Contract management of consultants; and
- Report writing



The CCF has been hosted by the following organizations:

2008-2010 - World AIDS Campaign, Amsterdam, Netherlands

2010-2012 - ICASO, Toronto, Canada

2013-2021 - Asia-Pacific Network of People Living with HIV/AIDS (APN+), Bangkok, Thailand



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This PCB NGO Delegation primer is based on the 47th PCB NGO Report, "Engagement, Evidence and Impact: 25 years of the NGO Delegation to the UNAIDS PCB."

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Photos courtesy of Communication and Consultation Facility (CCF) and UNAIDS Communication and Global Advocacy Team.



For details on the NGO Delegation and its work, please visit our website and social media pages:

Website: <https://unaidspcbngo.org/>

Facebook: <https://www.facebook.com/ngodelegationpcb>

Twitter: <https://twitter.com/ngopcb>