

*United Nations General Assembly  
Special Session on HIV/AIDS (UNGASS)*

# **A Guide for Meaningful Involvement of NGOs and Civil Society**

PREPARED BY THE INTERNATIONAL COUNCIL OF AIDS SERVICE ORGANIZATIONS (ICASO)

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## **Introduction**

For the first time since the start of the pandemic, the United Nations General Assembly will be holding a Special Session on HIV/AIDS. Every member country of the United Nations will be sending a delegation. NGOs should participate in some way in the Special Session because (a) the Special Session will produce a Declaration of Commitment that could set the tone for the global response to the epidemic over the next decade; and (b) the Special Session will focus world attention on the pandemic. The purpose of this guide is to assist you to advocate to be part of (or to influence) your national delegations, and to describe other ways in which you can participate in this historic process. This guide is available by email and through the Internet (see separate box). Please photocopy it and pass it on to other people in your organization and in other organizations. Please note: This Special Session is being organized very quickly (sessions of this type usually have a two-year lead time), so new information is becoming available almost on a daily basis. This guide is based on the latest information available at the time of writing.

“ We must make people everywhere understand that the AIDS crisis is not over; that this is not about a few foreign countries, far away. This is a threat to an entire generation; this is a threat to an entire civilization....the General Assembly Special Session will provide us with an occasion as never before to face up to our responsibility to future generations, and take decisive action now to turn back the progress of this terrible disease.”

– *Kofi Annan, Secretary-General, United Nations*

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## SECTION I

# What is the United Nations General Assembly Special Session on HIV/AIDS (UNGASS)?

### A. Overview

In October 2000, the General Assembly of the United Nations (UN) adopted a resolution calling for a Special Session to review and address HIV/AIDS in order “to secure a global commitment to enhance coordination and intensification of national, regional and international efforts to combat it in a comprehensive manner.”

There are three key documents associated with the UNGASS process:

- ◆ Report of the Secretary-General
- ◆ Issues Paper
- ◆ Declaration of Commitment

There are three key meetings associated with UNGASS:

- ◆ First Informal Consultation Meeting – February 26-March 2, 2001
- ◆ Second Informal Consultation Meeting – May 21-25, 2001
- ◆ Special Session – June 25-27, 2001

All three meetings are scheduled to be held in New York City.

Each country’s mission to the UN has been heavily involved in preparations for the Special Session. People from the missions have been meeting twice a week.

### B. The Documents

#### Report of the Secretary-General

(copies available on the UNAIDS website at: <http://www.unaids.org>)

This 29-page document, which was issued on February 20, 2001, is a summary of the HIV/AIDS situation today and its impact on human development. It examines, at a fairly general level, some of the main issues in the pandemic and provides an introduction to the more detailed or technical issues to be covered in round table discussions. The report describes the epidemiology of HIV/AIDS, its social and economic consequences, its impact on development and health-related indicators, national and regional responses, and lessons that have been learned over the past twenty years. The report also mentions the most pressing HIV/AIDS-related challenges facing governments, civil society and inter-governmental and UN bodies.

## **Issues Paper**

The Issues Paper will be a shorter, working document. It is expected to be released in late February or early March. The Issues Paper is expected to list previous formal commitments made by governments that are relevant to HIV/AIDS; describe priority HIV/AIDS issues; propose new government commitments to address these priorities; and present a set of targets to ensure that progress towards those commitments can be monitored.

## **Declaration of Commitment**

At the conclusion of the Special Session, all government delegations will jointly sign and issue a public Declaration of Commitment. The Declaration will be based on the issues raised in the Report of the Secretary General and the Issues Paper. It will be agreed upon by consensus among the member states' delegations. However, most of the work of drafting the Declaration will be done during the preparatory process for the Special Session.

## **C. The Meetings**

### **First Informal Consultation Meeting – February 26 – March 2, 2001**

The purpose of this preliminary, open-ended, informal consultation meeting of government delegates is to discuss the Report of the Secretary-General, and to talk about what should be included in the Declaration of Commitment. It is possible that a draft Declaration will be produced based on the results of this meeting.

### **Second Informal Consultation Meeting – May 21-25, 2001**

The second informal consultation meeting will review the draft Declaration of Commitment. The draft that emerges from this meeting may be very similar to the final draft endorsed by the General Assembly. It is unlikely that substantial changes to the declaration will be introduced at the Special Session itself because this would leave insufficient time for adjustment, agreement and adoption during the Session.

### **Special Session – June 25-27, 2001**

During the Special Session, there will be plenary sessions involving all delegations. There will also be four smaller round table discussions, one on each of the following topics:

#### **Round Table 1 – HIV Prevention and Care**

*Including:*

- Development of microbicides
- Improved access to care and treatment (including drugs)
- Improved health infrastructures
- Scientific research
- Vaccine development

## **Round Table 2 – Human Rights and HIV/AIDS**

*Including:*

- HIV/AIDS stigma
- Gender specific impacts of HIV/AIDS (especially women and girls, but including men and men who have sex with men)

## **Round Table 3 – The Social and Economic Impact of the Epidemic and the Strengthening of National Capacities to Combat HIV/AIDS**

*Including:*

- Development of national action plans
- Organizational survival of key governmental and civil society institutions in high-incidence countries
- HIV/AIDS as a security issue

## **Round Table 4 – International Funding and Cooperation**

*Including:*

- Debt relief
- Expanded public/civil society sector partnerships (including pharmaceutical industry)

“ In the name of PWAs, I demand that nations demonstrate a strong and clear desire to enact change and that they become involved. I demand that the international donors invest the means necessary to do so. This conference should be the occasion to coordinate political and financial efforts, not the enactment of a fictitious solidarity.”

– *President of Club des Amis, an association of people with HIV in Côte D'Ivoire*

## SECTION II

# How Can Your NGO Participate?

Accredited NGOs will be allowed to participate directly in the Special Session itself, and may be allowed to participate on a limited basis in the preliminary consultations. Accredited NGOs are (a) NGOs that already have consultative status with the Economic and Social Council of the UN and that have applied to be accredited to the Special Session; (b) NGO representatives that are delegates to the Programme Coordination Board of UNAIDS; and (c) other NGOs that have been or will be accorded special authorization to attend the Special Session.

If you are not one of the accredited NGOs, it is important that you still actively participate in the UNGASS preparatory process. Below, you will find various options and suggestions on how and when you can do this. Many of these suggestions are useful for accredited NGOs as well.

### Accreditation

There is still time for your NGO to be accredited to participate directly in the UNGASS process. For more information, write to Health Development Networks (HDN) at: [ungass@hdnet.org](mailto:ungass@hdnet.org) or the International Council of AIDS Service Organizations (ICASO) at: [info@icaso.org](mailto:info@icaso.org)  
**Deadline: 23 March 2001**

### A. Advocate to Be Part of Your National Delegation

Hopefully, each UN member country will send a senior delegation to the Special Session. In some cases, national delegations may participate in the informal consultation meetings. Their opinions and presentations will influence the overall outcome of the meeting. You should be lobbying your government to ensure that its delegation includes representation from NGOs in your country, particularly organizations of persons living with HIV/AIDS. Here are some tips on how you might approach this:

- ◆ Contact your UNAIDS Country Programme Advisor or Focal Point, if there is one, to obtain information and to identify who you need to contact in your country.
- ◆ Contact people you know in your National AIDS Control Programme, or the ministry of Health, or other relevant departments, to lobby for NGO representation.
- ◆ Write a letter to the appropriate officials in your country (perhaps the President or Prime Minister, the Minister of Health, or the Minister of Foreign Affairs) listing the arguments for including NGO/PWHA representation on your country's delegation. Please see separate box (next page) for ideas for your letter.
- ◆ Contact other NGOs in your country in order to develop a common strategy for this lobby effort. Get together with these NGOs to discuss which individuals could best represent the NGO sector on the national delegation.
- ◆ Go public with your demand that your country's delegation include the NGO sector. Take some time to explain to journalists and other media organizations why this is important.

## B. Influence Your Government's Participation

Whether or not NGO representatives are included in your country's delegation, you can influence the positions that your government takes on specific HIV/AIDS-related issues building up to the special session. Here are some suggestions for how to go about this:

- ◆ Get a copy of the Report of the Secretary-General, the UNGASS Issues Paper and working drafts of the Declaration of Commitment as they are issued. The Report of the Secretary-General is available now on the website of UNAIDS at <http://www.unaids.org>.
- ◆ Look at some of the feedback other NGOs are giving in response to these documents.
- ◆ Meet with other NGOs in your country to work out a common position and strategy for influencing your national delegation.
- ◆ Ask for a formal meeting between NGOs in your country and the members of your national delegation. The meeting should include a representative of your ministry of Foreign Affairs. The meeting should happen well before Special Session takes place, and preferably before the final preliminary consultation meeting (May 21-25, 2001).
- ◆ Before the meeting with your national delegation, identify what you and others think are the priority global HIV/AIDS issues. When you meet the delegation, ask them what issues they are planning to raise at the Special Session. If the delegation does not mention some of the priority issues that are on your list, ask them to raise these issues. Make other suggestions concerning what positions your government should adopt and promote. You may want to prepare a written description of the priority issues and positions (see next bullet).
- ◆ Prepare a national NGO position paper outlining the critical issues and making recommendations concerning the positions your government should promote at the Special Session.
- ◆ Submit the position paper to the people in charge of your country's HIV/AIDS programme, to your country's ambassador to the UN, to other NGOs and to Break-the-Silence, a dedicated email discussion forum set up for NGOs to discuss the Special Session (see separate box on the next page).

### Letter re NGO Representation

Here are some of the main points that you should include in the letter you send to your government asking it to include NGO representation in its delegation to the Special Session:

- This is the first time since the beginning of the HIV/AIDS pandemic that the United Nations General Assembly is holding a Special Session on HIV/AIDS.
- The Special Session will produce a Declaration of Commitment that could have a significant impact on the response to HIV/AIDS both in your country and internationally.
- The non-government sector plays a critical role in the response to HIV/AIDS in our country. It is very important, therefore, to ensure that our country's delegation to the Special Session includes representation from the NGO sector.
- As more is understood about the HIV/AIDS epidemic, greater emphasis is being placed on the value of community-based experience and expertise. Governments and NGOs must work closely together to launch the strongest and most effective response possible. Working together around the Special Session is an important part of this collaboration.

## C. Contact Accredited NGOs with Your Issues

Whether or not a representative of your NGO can attend the Special Session, and whether or not you have an opportunity to influence the positions taken by your government, you should contact accredited NGOs to make sure your country's and community's issues are heard. The accredited NGOs that are taking part in the UNGASS meetings in person are the eyes and ears of HIV/AIDS NGOs around the world. You should use them to channel information and perspectives into the UNGASS process, and you should call on them to update the NGO community about progress and developments. This is particularly true of the NGO delegates to the UNAIDS Programme Coordinating Board, who may have some privileged access to some of the UNGASS-related meetings. You should contact the accredited NGOs directly (see Section III for more information on whom to contact) or through Break-the-Silence, the e-mail discussion forum.

## D. Provide Feedback on UNGASS Documents

As indicated above, you will have some opportunities to react to the key documents associated with this Special Session. When these documents are released, it is important that you provide feedback quickly. Your feedback should be directed to (a) your national delegation, (b) other national delegations, and (c) accredited NGOs taking part in the Special Session. You should consider writing to any or all of these groups with your feedback and comments. You can also make your views known through Break-the-Silence, the email discussion forum.

## E. Develop a Media Strategy

There will be a lot of media coverage of the Special Session and of the preparations for it. This is an excellent opportunity to get your message out. The media will be looking for local and national angles to the international stories emanating from the UN. Your message can be about the Special Session itself, or about HIV/AIDS in your own city or country.

### Break-the-Silence

Break-the-Silence is a dedicated NGO and civil society e-mail discussion forum established specifically to support transparent and open NGO participation in the Special Session. Issues raised through contributions to this forum will be consolidated and made available to accredited NGOs, government delegations, UN organizations and the media.

To join Break-the-Silence, send an e-mail message to: [join-break-the-silence@hdnet.org](mailto:join-break-the-silence@hdnet.org)

You can find archival messages (copies of all messages to Break-the-Silence) as well as links and background information and documents on UNGASS on the website of Health and Development Networks (HDN), the organization that hosts the e-forum, at: <http://www.hdnet.org>

If you do not have access to e-mail or the Internet, contact an NGO in your area that has access to help you obtain the information distributed through the forum. If you are an NGO receiving information from the Break-the-Silence forum, you may want to display (and translate) some of the postings in your centre or offices, or distribute them to your clients and NGO partners. If local issues and priorities are raised and discussed in local languages, you could translate short summaries and send them to the e-forum to make sure these perspectives are heard.

Break-the-Silence is provided free of charge to all users. For information, write to [ungass@hdnet.org](mailto:ungass@hdnet.org).

You should start to contact local journalists now, to find out who will be covering the special session for various media outlets. Keep them informed of NGO activities in your country or community. Arrange for key people in NGOs to be interviewed in the week or two before the special session and preparatory meetings. This will help to ensure that NGO perspectives are available when the attention of the media is focused on the session.

If you have a national NGO network, you should consider developing a collective NGO media strategy to help share the responsibility for contacting specific media outlets or individual journalists. If your organization already has a fairly high profile in your country, think about preparing two news releases highlighting the NGO perspective in your country. Good dates to release the news releases will be the weeks of May 14-18 June 18-22. Make sure to include contact details of people who are willing to be interviewed.

If the special session is covered by the media in your country, you could share those news stories with others through Break-the-Silence, the email discussion forum. This might help other countries and organizations mobilize their local media.

## **F. Start Planning Now for Actions You Can Take after UNGASS**

If the Declaration of Commitment issued by delegates to the Special Session is a strong and progressive document, NGOs may be able to use it as a powerful advocacy tool. Here are some tips for how you might approach this:

- ◆ Ask your government to organize a meeting with major NGOs to review the accomplishments of the Special Session.

### **Case Studies of NGO-Government Cooperation Around UNGASS**

Partnerships between the NGO sector and government have been critical to the development of effective national HIV/AIDS responses and strategies. The extent to which national delegations and NGOs are able to cooperate and work together will also be one of the most important aspects of the UNGASS Special Session. Some governments have an open approach to working with NGOs, while others are more inclined to limit their involvement. Inclusion of NGOs and persons living with HIV/AIDS in national delegations for UNGASS is a good example and an indicator of ongoing collaboration.

As part of its support to the UNGASS process, Health & Development Networks (HDN) is collecting short descriptions of NGO-government collaboration in the lead-up to the UNGASS meeting. This will help NGOs in other countries share ideas and real-life examples of how best to work with government delegations, and will also serve as a record of which governments were receptive to NGO involvement during the UNGASS preparations.

Some of the case studies present successful approaches, while others describe instances in which NGO-government relations have not gone well, or have not even begun.

Check the HDN website at:  
<http://www.hdnet.org>

for archives and summaries of case studies as they emerge. Case studies shall be summarized as an unofficial UNGASS working document.

If you would like to submit a short description of NGO-government cooperation around UNGASS in your country, please write to:  
[ungass@hdnet.org](mailto:ungass@hdnet.org)

- ◆ At that meeting, press your government to act on the commitments included in the Declaration of Commitment. Ask them how they intend to ensure that the targets spelled out in the declaration will be met at the national and regional levels in your country.
- ◆ Organize a media conference where prominent NGO leaders call on the government to implement the contents of the Declaration of Commitment in your country.
- ◆ In future, when an HIV/AIDS issue arises in your country, use the Declaration of Commitment to back up whatever position you are taking. For example, you can remind your government representatives of the commitments and targets they agreed to the UN General Assembly session.

## **G. Keep up to Date on Developments**

Events are unfolding very quickly with respect to the Special Session. You can stay on top of developments by subscribing to Break-the-Silence, the email discussion forum. If you have access to the Internet, you can also find background information and documents on various websites. See separate boxes for details.

### **About ICASO**

ICASO is a global network of non-governmental and community-based organizations whose mission is to:

- articulate and advocate the needs and concerns of communities and their organizations;
- mobilize communities and their organisations to participate in the response to HIV/AIDS;
- ensure that community-based organisations, particularly those with fewer resources and within affected communities, are strengthened in their work to prevent HIV infection, and to provide treatment, care and support for people living with and affected by HIV/AIDS;
- promote the greater involvement of people living with, and affected by, HIV/AIDS in all aspects of prevention, treatment, care and support, and research;
- promote human rights in the development and implementation of policies and programs responding to all aspects of HIV/AIDS.

ICASO - CENTRAL SECRETARIAT  
 399 Church Street 3th Floor  
 Toronto, ON  
 CANADA M5B 2J6  
 Telephone: (1-416) 340-2437  
 Fax: (1-416) 340-8224  
 E-mail: [info@icaso.org](mailto:info@icaso.org)  
[www.icaso.org](http://www.icaso.org)

## SECTION III

# Contact Information

There may be several hundred NGOs accredited to the Special Session. It is not possible to list them all here. You may be able to find a list of these NGOs on one of the following websites:

UNAIDS: <http://www.unaids.org/>

HDN: <http://www.hdnet.org/>

If you need assistance or more information, you can also contact one of the NGOs on the UNAIDS/UNGASS Civil Society Advisory Committee. Below is a list of the organizations and individuals on this committee.

### Organizations

Canadian HIV/AIDS Legal Network  
Dr. Ralf Jüergens  
Email: [ralfj@aidslaw.ca](mailto:ralfj@aidslaw.ca)

Conference on NGO Organizations (CONGO)  
Ms Renate Bloem  
Email: [rbloem@iprolink.ch](mailto:rbloem@iprolink.ch)

Global Business Council on HIV and AIDS  
Mr Julian Hussey  
Email: [Julian.hussey@gbcaids.com](mailto:Julian.hussey@gbcaids.com)

Global Network of People Living with HIV/AIDS (GNP+)  
Mr Stuart Flavell  
Email: [gnp@gn.apc.org](mailto:gnp@gn.apc.org)

Health & Development Networks (HDN)  
Dr. Tim France  
Email: [ungass@hdnet.org](mailto:ungass@hdnet.org)

International AIDS Society (IAS)  
Mr Lars Kallings  
Email: [kallings@swipnet.se](mailto:kallings@swipnet.se)

International Council of AIDS Service Organizations (ICASO)  
Mr Richard Burzynski  
Email: [richardb@icaso.org](mailto:richardb@icaso.org)

International Confederation of Free Trade Unions (IFCTU)  
Dr Sam Lyomoki  
Email: [slyomoki@parliament.go.ug](mailto:slyomoki@parliament.go.ug)

### For More Information

Please consult the websites of the following organizations for more information on UNGASS:

Health Development Networks (HDN)  
<http://www.hdnet.org>

International Council of AIDS Service Organizations (ICASO)  
<http://www.icaso.org/>

Joint United Nations Programme on HIV/AIDS  
<http://www.unaids.org/>

and the special UNGASS website established by the United Nations:  
<http://www.un.org/ga/aids/>

### Copies of this Guide

You can obtain copies of this guide on the website of the International Council of AIDS Service Organizations (ICASO) at:  
<http://www.icaso.org/>

and on the website of Health Development Networks (HDN) at:  
<http://www.hdnet.org>

Please make photocopies of the guide and pass them on to people in your organization and in other NGOs.

International Federation of Red Cross and Red Crescent Societies (IFRC)  
Dr Alejandro Bermejo  
Email: [secretariat@ifrc.org](mailto:secretariat@ifrc.org)

Society of Women Against AIDS (SWAA)  
Ms Salimata Niang  
Email: [swaainter@metissacana.sn](mailto:swaainter@metissacana.sn)

World Association of Girl Guides and Girl Scouts (WAGGGS)  
Ms Jennifer Chiwela  
Email: [paf@zamnet.zm](mailto:paf@zamnet.zm)

World Council of Churches (WCC)  
Mr Manoj Kurian  
Email: [mku@wcc-coe.org](mailto:mku@wcc-coe.org)

**NGO Delegates to the UNAIDS  
Programme Coordination Board**

**AFRICA**

Ms Alice Lamptey (Ghana)  
Email: [tvolamp@ghana.com](mailto:tvolamp@ghana.com)  
Ms Fernanda Teixeira (Mozambique)  
Email: [Cvm@mail.tropical.co.mz](mailto:Cvm@mail.tropical.co.mz)

**ASIA/PACIFIC**

Mr Charles Nigel De Silva (Sri Lanka)  
Email: [capilitto@hotmail.com](mailto:capilitto@hotmail.com)  
Ms O.C. Lin (China)  
Email: [oclin@asiaonline.co.net](mailto:oclin@asiaonline.co.net)

**EUROPE**

Mr Pedro Silverio Marques  
Email: [abraco@mail.telepac.pt](mailto:abraco@mail.telepac.pt)

**Latin America and the Caribbean**

Mr Ruben Mayorga  
Email: [oasis@gua.gbm.net](mailto:oasis@gua.gbm.net)

**NORTH AMERICA**

Mr Jairo Pedraza  
Email: [babaluaye@aol.com](mailto:babaluaye@aol.com)  
Ms Diane Riley  
Email: [rileydm@aol.com](mailto:rileydm@aol.com)

**AfriCASO - Africa**

ENDA Tiers Monde  
54, rue Carnot, B.P. 3370,  
Dakar SENEGAL  
Contact: *Moustapha Gueye*  
Tel.: (221) 823-1935  
Fax: (221) 823-6615  
E-mail: [africaso@enda.sn](mailto:africaso@enda.sn)

**APCASO - Asia/Pacific**

Malaysian AIDS Council  
12 Jalan 13/48A The Boulevard Shop Office  
off Jalan Sentul 51000 Kuala Lumpur  
MALAYSIA  
Contact: *M. Puravalen/Susan Chong*  
tel: (603) 4045-1033  
fax: (603) 4043-9178  
email: [apcaso@pd.jaring.my](mailto:apcaso@pd.jaring.my)

**EuroCASO - Europe**

Groupe sida Geneve  
17 rue Pierre-Fatio  
CH-1204 Geneva, SWITZERLAND  
Contact: *Florian Hübner*  
Tel: (41-22) 700-1500  
Fax: (41-22) 700-1547  
Email: [florian@hivnet.ch](mailto:florian@hivnet.ch)

**LACCASO - Latin America and the Caribbean**

Acción Ciudadana contra el SIDA –  
Av. Rómulo Gallegos, Edif. Maracay, Apto. 21,  
El Marqués Caracas 1071 - VENEZUELA.  
Contact: *Edgar Carrasco*  
Tel: (58-2) 232 7938  
Tel/Fax: (58-2) 235 9215  
Email: [laccaso@internet.ve](mailto:laccaso@internet.ve)

**NACASO - North America**

Canadian AIDS Society  
900-130 Albert Street  
Ottawa, CANADA K1P 5G4  
Contact: *Sharon Baxter*  
Tel: (1-613) 230-3580  
Fax: (1-613) 563-4998  
E-Mail: [sharonb@cdnaids.ca](mailto:sharonb@cdnaids.ca)

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