

Declaration of Commitment on HIV/AIDS and Political Declaration on HIV/AIDS:

A review on progress from the community sector

ENGLISH



This policy paper presents a review by the community sector on national AIDS responses in four countries and four regions. It summarizes the key findings, conclusions and recommendations based on research into community sector involvement and analysis of the 2008 national country reviews of the progress made on the 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration on HIV/AIDS.

Structure of the Report

This report is divided in two main sections:

SECTION A discusses the main findings in relation to the **involvement** of the community sector in the national processes to review and report on progress in achieving the Declaration of Commitment and the Political Declaration.

SECTION B discusses the main findings in relation to the **analysis of the content** of the national progress reports, identifying key issues covered or missing.

The report ends with a series of conclusions and recommendations to different stakeholders: the UN system, governments, and the community sector.

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- Regionally: the African Council of AIDS Service Organizations in Africa; the Asia Pacific Council of AIDS Service Organizations for Asia Pacific; AIDS Action Europe and Eurasian Harm Reduction Network in Europe and Central Asia; and in Latin America and the Caribbean, the Latin American and Caribbean Council of AIDS Service Organizations.

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A review on progress from the community sector

Based on reviews by the community sector nationally in Bolivia, Indonesia, Russia and Senegal, and regionally in Africa, Asia Pacific, Europe and Central Asia and Latin America and the Caribbean.

Summary

- i. Community sector reviews have shown that the quality of the national progress reports often reflect the quality and quantity of inputs from key stakeholders – the exclusion or tokenistic involvement of the community sector in many countries puts into question the validity of these countries' progress reports.
- ii. Governments and the UN need to provide support and remove any political, legal, and practical barriers to the meaningful involvement of the community sector in national consultation and decision-making processes.
- iii. The continued lack of appropriate indicators and data collection related to key populations most relevant to the dynamics of the epidemics, especially on human rights and legal protections, is a fundamental barrier to monitoring progress in implementing the commitments.
- iv. Based upon the 2008 national progress reports, governments and the UN need to assess the specific gaps in data that will be needed to complete the full range of Declaration of Commitment (DoC) indicators for 2011, with particular attention to those relating to key populations. Develop these indicators through consultative processes, including in collaboration with the community sector, and plan how to collect the relevant data.
- v. While progress has been made in many countries, including increased access to treatment, the inequity of provision and access, especially for the most marginalized and vulnerable populations, and the slow rate of progress, requires urgent action by governments.
- vi. Governments need to rapidly scale up their responses to AIDS, decriminalize key populations such as sex workers, men who have sex with men and people who use drugs, and ensure legal protections against discrimination of people living with HIV and violence against women and girls. Without this governments will fail to meet the commitment of universal access to prevention, treatment, care and support by 2010.



In the rural district of Josini, South Africa, a mother caring for five HIV positive children speaks about her issues and problems with several "Community Carers."

“Some in the community sector were concerned that their country progress report did not fully reflect their country’s true HIV situation.”

Introduction

1. This short paper summarizes the key findings, conclusions and recommendations of research into community sector¹ involvement in the 2008 review and reporting on progress towards the 2001 Declaration of Commitment (DoC) on HIV/AIDS of the United Nations General Assembly Special Session on AIDS (UNGASS) and the 2006 Political Declaration on HIV/AIDS. The paper covers experiences from diverse political and epidemiological contexts, based upon four national and four regional studies. This research was coordinated and supported by the International Council of AIDS Service Organizations (ICASO).

Background: DoC and Community Sector Involvement

2. The DoC, adopted by all UN Member States in 2001, provides a comprehensive framework to halt and reverse the HIV epidemic by 2010, with specific milestones for 2003, 2005 and 2010, and a mandate for multi-sectoral involvement [see Figure 1]. In 2006, the DoC was reaffirmed by the Political Declaration on HIV/AIDS, which committed to the achievement of universal access to HIV prevention, care, support and treatment by 2010. This also called on the UN General Assembly to hold a comprehensive review of progress towards the DoC in 2008 and 2011.

¹ Defined as individuals, groups or associations which are separate from the government and the private sector, and who undertake actions and present views in support of community members living with or highly affected by HIV and AIDS. Reference: ICASO, AfriCASO and the Alliance (May 2007), *Coordinating with Communities: Guidelines on the Involvement of the Community Sector in the Coordination of National AIDS Responses*.

Figure 1: Commitment to Community Sector Involvement in DoC Reviews

“Conduct national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and care givers, of progress achieved in realizing these commitments, identify problems and obstacles to achieving progress.”

Paragraph 94, UNGASS Declaration of Commitment

3. Accordingly, in June 2008, global progress towards the DoC is being assessed at a high-level meeting. National governments were requested to inform this meeting through the provision of Country Progress Reports by January 31st. This was guided by the Joint United Nations Programme on AIDS (UNAIDS), with *Guidelines on the Construction of Core Indicators* and a reporting template provided to facilitate an effective and inclusive process.

The Research: Scope and Methodology

4. To inform the high-level meeting, ICASO, on behalf of a coalition of organizations, coordinated a research project to explore the community sector’s involvement in and impact on the review of the DoC in diverse contexts. The research used a common analysis tool and combined extensive literature reviews (including all available country progress reports and shadow reports), interviews, questionnaires and meetings with key stakeholders. The research was implemented by community sector partners and carried out at two levels:
 - **National:** In Bolivia (by the Instituto del Desarrollo Humano-IDH), Indonesia (Yayasan PITA), Russia (International Treatment Preparedness Coalition for Eastern Europe and Central Asia) and Senegal (African Council of AIDS Service Organizations).
 - **Regional:** In Africa (by the African Council of AIDS Service Organizations), Asia Pacific (Asia Pacific Council of AIDS Service Organizations), Europe and Central Asia (AIDS Action Europe and Eurasian Harm Reduction Network) and Latin America and the Caribbean (by the Latin American and Caribbean Council of AIDS Service Organizations).



A volunteer demonstrates correct condom use to the students of Government Sr.Sec.School, Khuda Lahora, Chandigarh, India, under the Adolescent Development and Empowerment Project run by the Ministry of Sports and Youth Welfare, Government of India.

A

Key Findings:

Community Sector Involvement in DoC Progress Reporting

The first section of the research focused on the process of community sector involvement in the national review and reporting of progress in implementing the DoC. This includes who initiated the process, who was involved, the extent of and support for involvement, data sources and validation, and factors that facilitated and hindered involvement.

How Reviews Were Started and How Community Sectors Were Defined and Selected

5. In the majority of countries, the DoC review process was started by the government and UNAIDS. In **Africa** and most of **Latin American and the Caribbean** (LAC), it was typically started by the National AIDS Council (or similar entity), with technical and financial support provided by UNAIDS.
6. In a few countries, the review process was initiated by the community sector itself – such as in **Bolivia** where the national network of people living with HIV sent a letter to the National AIDS Programme encouraging action. However, in this same country, only those “selected” by the government participated in the review and reporting process. In **Liberia** the Network of AIDS Service Organizations (LINASO) sent a letter to the AIDS Commission to press them to engage in the progress review process. However, the AIDS Commission argued that due to the lack of a current National Strategic Plan, they could not engage in the drafting process.

7. In some cases, government and community engagement started in parallel, for example in **Indonesia**, where an initial community sector forum led to the identification of a small community task team, which then communicated with the National AIDS Commission and UNAIDS.
8. In some countries, previous mobilization served as platforms for engagement. In **Brazil**, community sector organizations created the “UNGASS Forum” in 2004; a space to discuss and strategize community sector activities related to the DoC and to closely collaborate with the government in the review and report preparation. In the **Dominican Republic**, a “Permanent Committee for UNGASS follow-up” was created in 2006, and has been working since then, providing technical support to different processes, such as the preparation of the Strategic Plan, the target setting process for Universal Access and the 2008 country progress report preparation.
9. In many instances, the start of the country progress report process and, in particular, the involvement of the community sector was “last minute”. This was the case in most countries in the **LAC region**. In the **Russian Federation**, the first time that the sector knew of the process was when a letter was issued in November 2007, stating that a consultant would be hired to facilitate its involvement. Full information was not provided to the sector until a conference on 23 January, despite the official deadline for country progress reports falling on the 31st day of the same month.
10. The definition of “community sector” was often not formally decided before the process began – in some cases leading to tensions. In **Bolivia**, while the community sector provided a broad self-definition (covering a range of groups directly and indirectly affected by HIV), a more narrow selection was made by the government for the review process (groups representing people living with HIV, sex workers and lesbian, gay, bisexual and transgender [LGBT] populations). The tension was made worse by the National AIDS Programme soliciting a formal representative of people living with HIV for the ongoing process, while only involving the sex worker and LGBT groups in a national meeting (and not in the overall review process). In **Argentina**, the sector did not have to define itself for this process, because the government entities were already working with key populations, such as people who use drugs (PUD), sex workers, and transgender persons, and recognized the involvement of the community sector as key to the success of the response.
11. In some cases, efforts were made to develop democratic community structures to manage the sector’s consultation and participation. In **Senegal**, one of the NGOs selected by the National AIDS Council to be part of the country progress report task team consulted first with the Observatoire (a community sector “watchdog” body) before accepting the invitation. In **Argentina**, a structure that was developed for the regional AIDS Conference, was used for this process. In **Colombia**, an “AIDS NGO roundtable” that has been in existence for some time now, provided a democratic process to select the participants to the report preparation.
12. However, in most countries in the **LAC region**, lack of transparency in the process to select community sector participants hindered many of the efforts of this sector and resulted in country progress reports that do not reflect the actual reality of the response.
13. An example of efforts to ensure transparency among the community sector was provided in **Indonesia** – where, for a workshop to gather information for the National Composite Policy Index (NCPI) Part B, the community task team issued both specific invitations to some organizations and an open invitation to

the entire sector. In the **Russian Federation**, despite the short timeframe, the International Treatment Preparedness Coalition took responsibility for coordinating the community sector's involvement. This included disseminating an appeal for information via mailing lists and developing a web page devoted to the DoC.

14. Indeed, in several contexts, the 2008 process made increasing use of e-communication to facilitate community consultation. This included a web blog in the **Philippines** and an e-column run by the **China** HIV/AIDS Information Network. The latter provided a focal point for the posting of information from UNAIDS, ICASO, and others, and contributed to achieving input from 108 community sector groups from 20 provinces into the NCPI Part B.

Process For, and Extent Of, Community Sector Involvement

15. Although the exact process for reporting on the DoC varied from country to country, it was broadly divided into four phases: initiation (including the appointment of a “task team” or core group); data collection; data analysis/report writing; and report validation. In countries such as **Nepal**, a “road map” was drafted to guide stakeholders through the phases. In **Bolivia** the government organized a workshop to present the plan to develop the report, including defining the indicators. In **Guatemala** it was recognized that having enough time between the invitation and the different consultations/meetings really helped the sector to be fully involved and therefore have a country progress report that reflects the reality of the country.
16. In turn, within each phase, the quality and quantity of stakeholder consultation varied greatly – particularly in relation to the community sector. For example, while some task teams featured significant and equitable community sector involvement, others did not. In **Senegal**, the task team comprised seven members, including three from general civil society and one from the network of people living with HIV. In contrast, in the **Russian Federation**, the group that drafted the country progress report had nine members, but only one (a consultant for UNAIDS) represented the community sector. In some cases, such as **Guyana**, the community sector representatives did not know how they were selected to be part of the review and reporting process.
17. In some contexts, the extent of the community sector's involvement in the DoC process provided a “proxy indicator” for its participation in the overall national response to AIDS. Generally, countries with established mechanisms of partnership for policy-making – such as multi-sectoral National AIDS Committees – were able to use these to facilitate input into country progress reports. This was the case in most countries reviewed in **Latin America and the Caribbean**. However, in some contexts, there was a sense of disconnect between the DoC review and ongoing dynamics. This was apparent in **Cambodia**, where, despite 170 community groups participating in the UNGASS process, some respondents maintained concerns about the low level of community involvement in the overall development and monitoring of national policies.
18. Some questions were raised about community sector involvement being too selective – both politically and geographically. In **Lithuania** only information from one specific grouping of NGOs was considered in the country progress report process, while organizations beyond the capital were not involved – leading one respondent to conclude that “*therefore, in no way can it be called a country progress report.*” In the **LAC region**, some reported that only organizations from the capital were included; this was the case in **Colombia** and **Mexico**.

19. Concerns were raised – for example in shadow reports and key informant interviews from **Asia Pacific** – that community involvement and consultation was significantly constrained by short timeframes. This was the case in **Brazil** and **Panama**, where the community sector was invited to be part of the process to prepare the official country progress report, but in the end, the report was not validated, with claims of time constraints. However, in other countries, relatively low engagement in some of the review phases was seen to partly relate to the sector itself. For example, in **Senegal**, despite the National AIDS Council inviting 15 community sector groups to participate in a two-day consultation to launch the review, only three attended.
20. Comparisons of official and shadow reports of the DoC process also reveal some different *perceptions* about community sector involvement. The shadow report for **Indonesia** notes that participation “*seemed symbolic or tokenistic in many senses. In some processes, community was only involved in the last phase of the process, so the civil society or community activists were not able to fully contribute.*” Yet, although the official country progress report notes a similar concern, it attributes it, in part, to the sector’s low capacity to engage with national policy-making. In most of the official progress reports in **LAC**, it was reported that there was community involvement, although no details were provided. As exemplified above, this involvement varied in quality and quantity and in most cases did not include participation in the validation of the report.
21. With respect to “shadow” or parallel reports, some countries in **LAC** agreed to include these reports as annexes to the official report (**Brazil** and **Chile**) but did not incorporate information provided by such reports in the official country progress report. In **Uruguay**, the community report was incorporated into the official report. In **Argentina**, it was not even considered by the government.

Involvement of People Living with HIV and Other Key Populations

22. The involvement of people living with HIV and other key populations² also varied greatly within DoC reviews. In most countries in the **LAC region** organizations representing people living with HIV and other key populations participated in the process, although the extent of such participation (and the impact) varied from country to country.
23. In some cases, proactive steps were taken. For example, in **Nepal** – where HIV prevalence is over 50 percent among Injecting Drug Users (IDUs) in some cities – the national task team involved people who use drugs and people living with HIV. In **Kenya**, the government appointed a specific “Civil Society and Most-At-Risk Engagement Committee” as part of the UNGASS process, involving general community sector groups alongside men who have sex with men (MSM) and sex workers.
24. In **Mexico**, although the country progress report reflects that there is full integration and participation of the community sector, in particular of key populations, the reality is that the community sector was only invited to fill out a questionnaire, and not to participate fully in the preparation of the report.
25. Once more, there were differences in *perceptions* between the country progress reports and feedback from key populations themselves. In **Lithuania**, while the country progress report claimed multi-sectoral collaboration (with the findings discussed in a large forum involving people living with HIV), the people themselves raised concerns that in fact, part of the questionnaire issued to civil society was only available in English (significantly restricting participation), while some key actors, such as the Lithuanian Gay League, were neglected throughout.

² ICASO defines key populations as groups of people who are key to the dynamics of, and response to HIV and AIDS. These populations include people living with HIV, orphans and vulnerable children, women and girls, youth, sex workers, people who use drugs, men who have sex with men, transgender people, migrants, refugees and prisoners.

26. Few country progress reports specify the efforts made to involve people living with HIV and other key populations, even though some noted the increasing number of such groups. The country progress report for **China** estimates that there are now 400 groups of people living with HIV, and noted that their involvement in the national response to AIDS is constrained by the lack of a supportive legislative framework. Yet, the report did not provide information about how people living with HIV were involved in the development of such a framework. However, in the same country, proactive and welcome steps were taken by the community sector's UNGASS Working Group to hold consultations specifically focused on issues relating to treatment, people who use drugs, and sex workers.
27. Indeed, once more, the level of involvement of key populations in the country progress report process often reflected the status of such groups within wider action on AIDS. This was exemplified in **Fiji** where it was noted that *"while some most-at-risk populations have been represented in the National Strategic Plan, this has been tokenistic at best ... Six NGOs who are significant stakeholders were excluded from the Country Coordinating Mechanism during the Fiji Global Fund Round 7 process ... civil society representation on the [National AIDS Council] are currently government appointees."*

Engagement of Other Sectors and Their Support for Community Sector Involvement

28. The extent of multi-sectoral engagement in the country progress report process, and in turn, their commitment to community sector involvement, varied considerably. In **Indonesia**, for example, almost all stages were carried out through a partnership of the government, UNAIDS and the community sector [see Figure 2], while the private sector was not involved. This was the case in most of the countries in **Latin America and the Caribbean**.
29. The support of UNAIDS and other UN agencies, varied, in the case of **Africa, Latin America and the Caribbean** and **Eastern Europe** and **Central Asia**, "from none to 100 percent." In many countries, UNAIDS played a vital catalytic and facilitative role, while stepping back from substantive input. For example, in **Armenia** it provided technical support for the collection and analysis of information, while leaving other tasks to a sub-group of the Country Coordinating Mechanism (CCM). In **Colombia**, UNAIDS initiated the process, inviting different stakeholders, including people living with HIV (PLHIV) and other community sector representatives. In **Chile**, the first information about the reporting process was shared within the UN Thematic Group. In the **Dominican Republic**, the support role of UNAIDS was catalogued as "extraordinary" and key to allowing community sector involvement in the report process.
30. In the **Russian Federation**, UNAIDS hired a consultant (from the Russian Harm Reduction Network) to liaise between the country progress report Working Group and the community sector. This person played a critical role, including supporting the sector to prioritise its multiple concerns. Meanwhile, in **China**, UNAIDS provided both financial and moral support to enhance community sector involvement.
31. The country progress report process highlighted ongoing tensions between the expectations and capacities of stakeholders. In **Asia Pacific**, it showed how community representatives are expected to participate in high level policy processes, but are often not given capacity building or financial reimbursement. The latter was exemplified in **Indonesia**, where the shadow report cites instances of people living with HIV being invited to national meetings without support to prepare their contribution.

Figure 2: Process of Collaboration, Indonesia

In Indonesia, the key steps for multi-sectoral collaboration during the DoC review included:

- **July 2007:** Community sector sets up the Indonesian UNGASS Community (IUC) and communicates with UNAIDS and National AIDS Commission (NAC), calling for meaningful involvement in country progress report process. The IUC commits to producing a report, agreeing to review the official country progress report before deciding whether to integrate its report or submit it separately.
- **July 2007:** UNAIDS and NAC contact the IUC to consult on getting input for NCPI Part B. The IUC proposes leading the gathering of input, including by co-facilitating a data input workshop, selecting community sector representatives and reviewing the final results.
- **September - December 2007:** Workshop is co-facilitated by UNAIDS, NAC and the IUC and involves a range of capital-based community participants. Those not able to attend are sent NCPI Part B questionnaire. Working group (of monitoring and evaluation staff of UNAIDS and NAC, plus the IUC) clarify results of the workshop. Results are shared with community sector through national mailing lists and harm reduction network.
- **January 2008:** UNAIDS and NAC conduct a workshop, inviting all partners to review the draft country progress report and gain agreement from the NAC's executive. Also, the IUC hold a second forum to discuss and verify the community report. The IUC requests to see the final draft of the country progress report, but NAC does not receive request. NAC submits country progress report to UNAIDS.
- **February 2008:** The IUC launches community report, disseminating it to key stakeholders through e-mail.

Processes to Collect and Review Data and Validate Country Progress Reports

32. Some improvements were reported in the mechanism to collect data for this reporting period of the DoC. In **Indonesia**, the process was carried out through the existing Monitoring and Evaluation working group of the National AIDS Commission – making it simpler and more integrated than before. In the same country, however, there were concerns about the limited breadth of sources used – with donor agencies, their implementing partners and government agencies predominating. The final country progress report did not systematically incorporate information from the community sector (as it was incorrectly assumed to be included in the donors' input). It only quoted one community resource and only used government examples of best practice.
33. In the **LAC region**, most countries had community participation in every stage of the process, except the validation of the report. Most people interviewed for the report complained that after filing out questionnaires and attending meetings they had expected to review the final country progress report before it was submitted to UNAIDS. Only in **Chile** and **Guatemala** did a validation workshop/meeting take place that helped in improving the report. Most of those in the countries where no validation occurred, reported that the final reports submitted to UNAIDS did not fully reflect the reality of the countries. In **Guyana**, only one organization was invited to the validation of the report, excluding the group of PLHIV and others who had been involved in the report preparation.

34. In some countries, the data used to develop the country progress report was recognized to be out of date, such as in **Mauritius**, where the primary source for the knowledge and behaviour indicators, including those for key populations, was based on research conducted in 2004.
35. In some cases, the community sector took the initiative itself to collect relevant data. In the **Russian Federation**, NGOs, including members of the Russian Harm Reduction Network, responded to a government request for quantitative data. Meanwhile, NGOs also provided input into two specific areas of reporting prioritized by the International Treatment Preparedness Coalition – “best practice” and “key problems and solutions.” Based on the feedback, the Coalition consolidated 20 key points and forwarded them to the Working Group, as part of developing the country progress report.
36. Overall, little information was provided in country progress reports about the exact process used to analyse and agree on the data. In **Indonesia**, during a national workshop to fulfill NCPI Part B, a scoring system was used – with participants encouraged to voice their opinions and to offer arguments and counter-arguments. Although voting was an agreed option, it was not required, as consensus was reached on every point.
37. Frustration was expressed that, at several key steps in the process, the community sector was not given the full or most recent information related to the report. In **Bolivia**, the participants at a workshop to develop the country progress report were not given access to the full data that had been collected, nor told the methodologies used for its collection.
38. There was particular confusion about when and how drafts and final texts of country progress reports were ready. In some cases, there was transparency – such as in **Armenia**, where the draft country progress report was published on the website of the National Center for AIDS Prevention, enabling everyone to give feedback to the CCM Working Group. In other cases, the process was less open. For example in **Kyrgyzstan**, although the community sector was involved in collecting and analysing the data for the country progress report, it was unclear as to whether the officially endorsed report had been submitted to UNAIDS. Indeed, respondents in several countries expressed concern that their country progress report was not published promptly on the UNAIDS website and/or was not published in full.

Factors Influencing Community Sector Involvement

39. The research has highlighted a number of important factors that facilitate the involvement of the community sector in reviewing progress towards the DoC. Examples of these include:
 - The community sector itself taking the initiative to set up its own coordination group in advance, assertively voicing its right to be involved, and having strong systems in place to select representatives and consult with constituents.
 - Governments and UNAIDS providing a ‘roadmap’ for systematic, multi-sectoral involvement, entrusting the selection of community sector representatives to the sector itself, and providing clear and easy-access materials about the DoC and national monitoring systems.
40. In **Guatemala**, it was highlighted that a process with clear timelines, and sufficient time to consult, to give and receive feedback and to mobilize the community sector, resulted in a comprehensive and inclusive process that produced a report that reflected the views of the country as a whole.

41. However, the research also demonstrated that there remain multiple and significant barriers to the full and meaningful involvement of the community sector. This includes lack of access to information and official systems to support involvement, and lack of support to strengthen community systems [see Figure 3].

Figure 3: Examples of factors hindering community sector involvement in DoC reviews

Lack of Access to Information and Official Systems to Support Involvement

- Limited information about the DoC and its importance to the community sector (**Indonesia and the Latin America and the Caribbean**).
- Lack of equitable communication between community sector and government (**Russian Federation**).
- Data and information gathering materials not translated into local languages (**Lithuania**).
- Short, unrealistic timelines that made consultation impossible (**Bolivia and Uruguay**).
- Large volume of information involved – requiring time and expertise (**Russian Federation**).
- Lack of time or motivation by government authorities to involve community sector (**Bolivia**).
- Methodology to collect, analyze and validate data was not clear and hindered efforts to get consensus (**Uruguay**).
- Absence of a supportive legal framework to enable community sector to register, receive funding, etc. (**Vietnam**).
- Lack of coordination between local/central levels in DoC reporting process (**Romania**).
- Lack of access by remote community groups to urban-based decision-making (**Asia Pacific**).

Lack of Support to Strengthen Community Systems

- Lack of knowledge, skills and will among communities to engage in policy work (**Armenia**).
- Lack of ownership of the UNGASS review process by the community sector (**Mexico**).
- Lack of community sector involvement in the overall national response to AIDS, especially monitoring and evaluation (**Russian Federation**).
- Lack of formal community sector platform to coordinate response and select representatives (**Indonesia**).
- Lack of a national network of people living with HIV (**Vietnam**).
- Lack of continuity in representation of community sector (**Indonesia**).
- Dominance of members of community sector, such as those with strong relations with government (**Asia Pacific**).
- Community sector representatives not being reimbursed for time and expenses (**Asia Pacific and Mexico**).

Limited access to relevant financial and technical resources, including from international agencies (**Asia Pacific, Uruguay, Mexico and Colombia**).



Thai activists call for international solidarity in support of drug users at a protest in Thailand.

B Key Findings: Content of National Progress Reports

The second part of the research focused on the results of the reviews of progress of implementation of the DoC, particularly in relation to issues most relevant to the community sector. This includes assessing the completeness of reporting, relevance to actual epidemics, quality of reports and impact of community involvement.

Completeness of Reporting Against Core Indicators and National Composite Policy Index (NCPI)

42. The completeness of the country progress reports for 2008 was reported by the community sector to be very mixed, including in terms of the extent to which they covered the 25 Core Indicators and addressed the NCPI. In regions such as **Europe** and **Central Asia**, only a few countries (mostly in Western Europe) followed the reporting guidelines provided by UNAIDS strictly – making it challenging to compare results across countries. In **Africa** and **Latin America and the Caribbean**, although the countries researched tended to follow the guidelines, there was no uniform completion of all sections or provision of all annexes.
43. On a simplistic level, the range in the depth of reporting was shown by the length of the country progress reports: from 5 pages for **Singapore** to 169 pages for **Papua New Guinea**. More significantly, the range was shown by the number of indicators reported upon. In some regions, such as in **Europe** and **Central Asia**, there was a general sense of more indicators being addressed in 2008, than in previous DoC processes. In other regions, the picture was more varied. For example, from the information available of the ten countries researched in **Africa**: all but one completed both the national spending and policy indicators (#1 and #2); two (**Burkina Faso** and **Gabon**) completed all of national programme indicators (#3-#11); and the majority completed the impact indicators (#22-#24, with #25 pending input on modeling from UNAIDS).

44. In individual countries, there were some significant limitations to the completion of indicators. In **Indonesia**, four of the core indicators were omitted due to a lack of appropriate national data, while a further five were not addressed due to the National AIDS Commission and UNAIDS considering them inappropriate to the context. The latter highlighted a tension relating the categorization of national epidemics – because, while Indonesia’s overall epidemic is concentrated, it has a generalized epidemic in one particular region.
45. In **Bolivia**, only a total of 12 indicators were addressed. This again reflected a lack of national data, but also the non-solicitation of information from the community sector, particularly in relation to “hard to reach” populations (such as men who have sex with men) that are key to the country’s concentrated epidemic.
46. Similarly, in **Lithuania**, critical indicators were omitted. As a respondent noted: *“The report lacks indicators of PLHIV access to medical and psychosocial services ... Problems for PLHIV are hardly covered at all.”* While a questionnaire had asked about issues such access to free and anonymous pre and post-test counselling, relevant data was not included in the final country progress report – a product that the same respondent concluded to be *“too abstract, not truthful.”*
47. Some countries recommended the addition of extra indicators in order to better assess priority areas for specific contexts. **Georgia** suggested two – coverage of substitution therapy for IDUs and coverage of specific ARV therapy for Hepatitis C patients – for countries where injecting drug use is a significant mode of transmission.

Reflection of National Epidemics, Results and Key Issues

48. In some cases, the country progress reports for 2008 enabled reporting on welcome increases in scale and impact relating to key areas of national responses to AIDS. One example was access to ARVs – where important achievements in scale were noted in many contexts, including **Asia Pacific and Latin America and the Caribbean**.
49. However, even with such a success, the country progress reports did not always tell the full story – such as the still low *proportion* of people living with HIV with access to treatment, the challenges to maintaining supplies of drugs and the low level of accompanying psychosocial services. Some country progress reports also did not fully explore issues of inequity in the provision of treatment. For example, in **Indonesia**, while only a quarter of all people living with HIV in need of treatment are on ARVs, the figure drops to just 1 percent for those that are people who use drugs.
50. More generally, some in the community sector were concerned that their country progress report did not fully reflect their country’s true HIV situation. Two particularly vital gaps/inadequacies were emphasised: key populations and human rights.
51. In multiple countries, country progress reports gave inadequate attention to key populations. In some, indicators were simply not selected, in others, gaps were due to the lack of existing or new data. Even where data was presented, country progress reports often lacked the detail to articulate exactly what the issues were and what was being done about them. For example, the 45-page report for **China** (where HIV particularly affects people who use drugs) included only three lines of mostly quantitative data

“... The lack of real commitment, as compared to the commitment on paper ... basically, we run out [of ARVs] on an almost monthly basis.”

Member of community sector, Indonesia

about needle and syringe distribution. It did not discuss the operation of, or access to related programmes. This is despite an International Harm Reduction Association report that states that “*in China, it is estimated that ... only 7% of people who inject drugs have access to NSP services in areas where they exist.*”

52. Similarly, in the **Russian Federation**, despite the community sector providing information relating to injecting drug use (such as the stigmatizing practices of doctors), such issues were not reflected in the final report.
53. Indicators relating to other specific key populations were missing in regions such as **Africa**. For example, data on the indicator relating to condom use by MSM was only provided in three out of the ten countries covered by the research. This was a particularly significant gap in countries such as **Senegal**, where, despite being relatively low among the general population (0.7 percent), HIV prevalence is 21.5 percent among MSM. While the epidemiological reality is recognised within the country’s National Strategic Plan for 2007-2011, the country progress report did not serve to advance discussions.
54. Gaps or inadequacies relating to human rights were particularly notable in regions such as **Asia Pacific**, where abuses continue to “fuel” concentrated epidemics that disproportionately affect key populations. Here, there was sometimes a sharp contrast between official country progress reports and other sources. For example, a shadow report by the Thai Treatment Action Group indicates how the government of **Thailand**’s “war on drugs” (involving harsh penal and extra-judicial measures) has affected not only the security of people who use drugs, but their willingness and ability to access HIV services.
55. While many countries report having laws that protect people living with HIV from discrimination, many still lack such legal protections. Even in cases where such protections do exist (either before or after the adoption of the DoC), people living with HIV and other key populations still face stigma and discrimination. Most countries have policies in place to ensure equal access to HIV-related services for vulnerable groups, but these same countries have laws or policies that impede access to HIV services, particularly prevention services. In **Latin American**, against the background of widespread homophobia, a high HIV prevalence has been found among men who have sex with men in several Central American countries.
56. In the African region, the lack of information on vulnerable populations undermined how information related to them was included (or not) in the country reports. Only in **Kenya**, is there updated information about most-at-risk populations reached by prevention programs. For example, in **Mauritius**, the primary source to inform indicators #7 to #21 was a study conducted in 2004. This study was conducted several years prior to the reporting period for UNGASS 2008.
57. Meanwhile, other country progress reports did not reflect current tensions between need and reality in relation to human rights issues. For example, in **Senegal**, where, as noted, support to MSM is prioritized in the National AIDS Plan, homosexuality remains a criminal act.
58. Where human rights issues were raised in official reports, it was clear that in some contexts, abuses relating to AIDS remain routine. The country progress report for **Malaysia** highlights how HIV tests are mandatory for migrant workers, with an HIV positive result risking deportation.
59. Examples of other gaps or inadequacies noted in country progress reports covered populations and issues as varied as gender, prisoners, orphans and vulnerable children, free HIV testing, prevention and the treatment of opportunistic infections.

Quality of Reporting and Impact of Community Sector Involvement

60. The overall quality of the country progress reports for 2008 varied greatly, with those based upon input from a wide spectrum of stakeholders tending to be more comprehensive and complete. In **Asia Pacific**, reporting was generally felt to have improved significantly since 2005, often reflecting improved data collection, enhanced political commitment and a greater willingness to include the views of the community sector. In **Indonesia**, the country progress report compared well to the previous report – being generally less complicated, while more inclusive and more reflective of “grassroots” involvement.
61. However, in many countries, such as **Kazakhstan**, the community sector felt that despite definite progress, the country progress reports could have been more accurate, useful and/or of a higher quality. In some instances, the challenges lay with the way in which the information was presented, for example with tables not facilitating comparisons between 2005 and 2007 figures or with data only being provided in percentages (restricting analysis of scale rather than just proportion). In other instances, the limitations were related to tone – such as in **Lithuania**, where the report only focused on information that would not discredit the country’s AIDS efforts. In **Guyana** the community sector felt that old mistakes (from previous consultations and report preparation processes) were repeated in 2007, such as the lack of multi-sectoral involvement in the validation of the information collected.
62. Many in the community sector expressed disappointment that much of the input that they provided during data collection was not reflected in the final country progress report. A particularly strong example was presented by the **Russian Federation** where, despite unprecedented opportunities for community sector involvement, the final report largely failed to address any of the issues that the sector had raised [see Figure 4].
63. In **Bolivia**, the community sector was particularly concerned that the data in the final country progress report not only failed to fully utilise its input, but was based on very limited sources. As such, it gave a misleading impression of the scale and nature of key issues, such as HIV prevalence and access to services for MSM and sex workers.

Figure 4: Community sector input not fully addressed in country progress report, Russian Federation

In the Russian Federation, the community sector raised 20 issues to be included in the country progress report. Examples included:

- The State’s lack of a clear position on harm reduction.*
- Challenges to the purchase and distribution of ARVs.
- Stigma and discrimination against IDUs by doctors.*
- Lack of a mechanism for involving people living with HIV and key populations in planning, implementing and monitoring response to AIDS.*
- Lack of a harmonized national strategy on AIDS.

*Indicates issue not addressed in the final country progress report. Other issues were partially or indirectly addressed.



Young people protesting in Eastern Europe.

Conclusions

64. Despite some important differences between countries and regions, a number of common conclusions can be drawn from the experiences and lessons documented within the research into the 2008 reviews of the DoC.

These include that:

- Overall, **awareness of and political leadership for the DoC** remains low among a variety of important stakeholders, including those within the community sector.
- In some countries, **significant progress** is being achieved in relation to the indicators specified by the DoC. In particular, the increased **provision of ARVs** in many countries is a concrete result to be warmly welcomed. In reality, however, the levels are still far from those required to save many millions of lives.
- In some countries, **community sector involvement** in DoC reporting is increasingly comprehensive and meaningful, while, in others, it remains minimal or tokenistic. For the majority of contexts, however, the experience lies somewhere between the two – with the sector involved, but in a relatively inconsistent and unsystematic manner, and in many cases only invited to “legitimize” the process.
- The existence of **established mechanisms or structures** (for example an AIDS Commission) that include the community sector facilitated their involvement in the review and reporting process.

- The quality of the final country progress reports often reflects both the quality and quantity of the **inputs gained from key stakeholders**. If a group of constituents – such as the community sector, and particularly key populations – has not been actively and meaningfully engaged, it affects the overall validity of the process and product.
- Many country progress reports illustrate countries’ willingness to acknowledge weaknesses in their national AIDS programmes and health sectors, such as the involvement of key populations. However, the reports also indicate that many of the most significant challenges to implementing the DoC lie beyond the AIDS/health sector and is part of **larger legislative, policy and resource issues**. These can only be resolved through significantly higher level, and more genuinely multi-sectoral, political and financial commitment.
- In particular, issues relating to **human rights and legal protection** continue to “fall through the cracks” of national responses to AIDS. Indicators largely fail to ensure that the monitoring of the DoC plays a significant role in improving the environment for rights-based approaches – including by bridging the gap between newer, more progressive international commitments relating to AIDS and existing domestic legislation that criminalizes or restricts drug use, sex work and sex between men.
- In some cases, the lack or poor quality of information to report on DoC indicators relating to **key populations** is influenced by underlying stigma and discrimination – reflecting a country’s lack of recognition of, or commitment to support such populations.
- Quantitative data to respond to the review of the DoC can only ever tell part of the story. While a number can state how many people are accessing a service, it can not explain why others are *not* – for example, due to stigma. Until such **qualitative issues** are addressed, there will only ever be limited progress in meeting commitments to addressing HIV and AIDS.
- **Capacity for monitoring and evaluation** remains low within the community sector and significantly limits its potential to engage in high level national processes such as reviewing progress towards the DoC. The challenges lie at both a practical level (such as how to develop useful and high quality community-level indicators) and policy level (such as how to advocate for community data to be incorporated into national reporting).



"Khote"/transgender sex workers at a truck depot.

Recommendations

- 63.** The findings and conclusions of the research lead to recommendations for three key groups of stakeholders involved in the review of the UNGASS DoC:

Stakeholder Group 1 – **UNAIDS, other UN agencies and international donors** should:

- 1.1.** Provide a clear and compelling explanation of what DoC monitoring involves, why it matters and how it links to other processes, such as Universal Access. There should be a special focus on countries demonstrating limited or no reporting in 2008.
- 1.2.** Ensure that at the country level, guidelines and other DoC materials are written simply and are easily accessible in appropriate formats and languages.
- 1.3.** Actively support the involvement of the community sector in the development of country progress reports and, where necessary, proactively and enthusiastically facilitate such involvement – especially with governments that are known to marginalise such stakeholders.
- 1.4.** Build understanding and capacity among government stakeholders about why and how the greater involvement of people living with HIV (GIPA) and other key populations should be achieved³.

³ Make use of existing supporting tools, such as "Coordinating with Communities: Guidelines on the involvement of the community sector in the coordination of national AIDS responses", ICASO, Alliance AfriCASO, 2007.

- 1.5. Support and mobilize resources for the capacity building of the community sector, especially key population groups, to strengthen their communications, consultation and representation systems.
- 1.6. Support the capacity building of all relevant stakeholders for monitoring and evaluation (M&E), including for the community sector and for the inclusion and analysis of community sector data.
- 1.7. Produce and disseminate good practice case studies of countries with effective community sector involvement in DoC processes, providing lessons learned and practical ideas for key steps.

Stakeholder Group 2 – **governments** should:

- 2.1. Develop and publish a calendar of action and budget for each two-year reporting period for the DoC, mapping out key milestones for consultation.
- 2.2. Demonstrate commitment to the meaningful involvement of the community sector, including key populations, not only in the DoC process, but the ongoing planning, management and monitoring of the national response to AIDS.
- 2.3. Ensure that the involvement of the community sector is facilitated at all steps in the DoC review process, for example by allocating a minimum number of seats within task teams and national workshops.
- 2.4. Implement the “Three Ones” Principles by coordinating one national monitoring and evaluation system for AIDS that integrates all relevant processes, including the DoC and universal access. Widely communicate the indicators and ensure that the system acknowledges and actually uses data from the community sector.
- 2.5. Strengthen national indicators on human rights, especially of people living with HIV and other key populations – to enable DoC implementation monitoring to play a more significant role in promoting a rights-based response to AIDS.
- 2.6. Based upon the 2008 country progress report, assess the specific gaps in data that will be needed to complete the full range of DoC indicators for 2011, with particular attention to those relating to key populations. Develop these indicators through consultative processes and plan how to collect the relevant data, including in collaboration with the community sector.
- 2.7. Address any practical barriers to the involvement of the community sector in national consultation processes. For example, give enough notice of meetings, communicate in local languages and reimburse participants’ travel costs.

Stakeholder group 3 – the **community** sector should:

- 3.1. Stay actively engaged in the UNGASS process, ensuring ongoing consultation with constituents and being a “watchdog” with regard to the extent to which the DoC indicators are being taken seriously and performance is improving.
- 3.2. Be proactive about *leading* national processes, such as for the DoC implementation review, rather than waiting to be invited. Practical steps can include: developing a self-definition of “community sector”; having an agreed process for selecting community representatives; and appointing an independent community “task team”.
- 3.3. Enhance the accountability and credibility of the sector by strengthening its communications platforms to consult with and represent wider constituents, in particular people living with HIV and other key populations.

- 3.4. Take proactive steps to increase the sector's capacity and involvement in national monitoring and evaluation, including by facilitating relevant technical support and advocating for the inclusion of community-level data in the country's monitoring and evaluation system.
- 3.5. Use the findings of the 2008 country progress reports to advocate for action to address specific gaps in national data and/or activities. Examples may include research into the needs of specific key populations or a review of human rights legislation.
- 3.6. Continue to develop high quality and comprehensive shadow reports on progress towards the DoC, to provide a valid and objective complement to official country progress reports.

"The research [...] demonstrated that there remain multiple and significant barriers to the full and meaningful involvement of the community sector. This includes lack of access to information and official systems to support involvement, and lack of support to strengthen community systems."

"Some in the community sector were concerned that their country progress report did not fully reflect their country's true HIV situation."

"The continued lack of appropriate indicators and data collection related to key populations most relevant to the dynamics of the epidemics, especially on human rights and legal protections, is a fundamental barrier to monitoring progress in implementing the commitments."

"While many countries report having laws that protect people living with HIV from discrimination, many still lack such legal protections. Even in cases where such protections do exist (either before or after the adoption of the DoC), people living with HIV and other key populations still face stigma and discrimination. Most countries have policies in place to ensure equal access to HIV-related services for vulnerable groups, but these same countries have laws or policies that impede access to HIV services, particularly prevention services."

"Governments need to rapidly scale up their responses to AIDS, decriminalize key populations such as sex workers, men who have sex with men and people who use drugs, and ensure legal protections against discrimination of people living with HIV and violence against women and girls. Without this governments will fail to meet the commitment of universal access to prevention, treatment, care and support by 2010."

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