ICASO
INTERNATIONAL COUNCIL OF
AIDS SERVICE ORGANIZATIONS

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Conference Paper related to provisional agenda item 4.1:

Community sector report on the process for setting national targets for universal access.

(Based on community reviews supported by the International Council of AIDS Service Organizations in Belize, Ghana, Nepal and Romania and regionally in Africa and Eastern and South-Eastern Europe and Central Asia)

ICASO's recommendations for action at this meeting – The Programme Coordinating Board should request UNAIDS to:

i. Provide greater clarity and guidance on what is meant by 'universal access', supporting national processes that include the community sector, especially key populations, to revise and validate ambitious and comprehensive targets.

ii. Increase the provision of direct financial and technical support, and mobilize additional support, to the community sector to facilitate and strengthen their involvement in universal access target setting and related national processes.

iii. Provide greater support to countries to conduct additional assessments to collect and disaggregate adequate and up-to-date data on the status of the epidemic and the response, particularly in relation to key populations.

Introduction

1. This conference paper is being submitted by the International Council of AIDS Service Organizations (ICASO) to the 20th UNAIDS Programme Coordinating Board. It summarizes the initial key findings and recommendations of a review of national processes to set universal access targets in over 30 countries. It particularly focuses on community sector involvement and their analysis of the targets set. A longer report that will also include analysis from Asia-Pacific and Latin America and the Caribbean will be available in four languages at a later date.

Background

Universal Access and involvement of key populations. [1]

2. On 2 June 2006, Member States at the 87th plenary meeting of the United Nations (UN) General Assembly adopted a Political Declaration on HIV/AIDS. Countries committed, among other measures, to set ambitious targets for the end of 2006 to scale up the response to the HIV epidemic towards the goal of reaching universal access by 2010. This process to set targets needed to be transparent and inclusive, with the full and active participation of, among others, vulnerable groups (see text box 1).

Text Box 1: The Political Declaration on HIV/AIDS, 2006

Paragraph 20:

"(We) commit ourselves to pursuing all necessary efforts to scale up nationally driven, sustainable and comprehensive responses to achieve broad multisectorial coverage for prevention, treatment, care and support, ***with full and active participation of people living with HIV, vulnerable groups, most affected communities****, civil society and the private sector, towards the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010."*

Paragraph 49:

"(We) Commit ourselves to setting, in 2006, ***through inclusive, transparent processes, ambitious national targets****, including interim targets for 2008 in accordance with the core indicators recommended by the Joint United Nations Program on HIV/AIDS, that reflect the commitment of the present Declaration and the urgent need to scale up significantly towards the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010, and to setting up and maintaining sound and rigorous monitoring and evaluation frameworks within their HIV/AIDS strategies."*

3. Broad involvement of all stakeholders, including the community sector, in setting clear and appropriate targets is important because it fosters ownership and accountability. It also provides a better understanding of the specific dynamics of national epidemics.

4. UNAIDS has supported most of the processes where countries have set national targets for universal access. In their Operational Guidelines they advocated for governments to fully involve the community sector in the process in order to *"help achieve effective outcomes and legitimate targets."*[2] In practice, however, it has not been clear how, or even if, the community sector was fully and actively involved – and, therefore, whether the targets are considered "legitimate."

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[1] ICASO has used the term "key populations" to refer to groups of people who are key to the dynamics of, and response to, HIV/AIDS. These populations include: people living with HIV/AIDS, orphans and vulnerable children, women and girls, youth, sex workers, injecting drug users, men who have sex with men, transgenders, migrants, refugees and prisoners.

[2] UNAIDS, *Universal access targets and civil society organisations - a briefing for civil society organisations.*

Methodology/Approach

5. In 2005-6, the International Council of AIDS Service Organizations (ICASO) supported community advocates in 14 countries to carry out shadow monitoring reports on the implementation of the Declaration of Commitment (DoC) made at the UN General Assembly Special Session on AIDS (UNGASS) in 2001.

6. Based upon the lessons learnt from this experience, ICASO developed a 4-year project to support community sector advocates to be involved in universal access target setting, implementation, and review processes. The overall goal s are to help ensure that the targets for universal access set at the country level are ambitious, reflect the epidemic and the needs of those most affected, and are achieved by 2010.

7. This conference paper is a component of phase 1 of this project in which ICASO is supporting country and regional analysis of the universal access target setting and implementation processes. Phase 1 involved a number of analytical methods, principally interview-based and written responses to a questionnaire designed by ICASO and stakeholder verification meetings and reviews of the findings in each of the four country studies. The analysis was undertaken at three levels:

- Four country-level case studies**:** Belize, Ghana, Nepal and Romania;
- Four regional-level reviews**:** Africa (13 countries[3]), Eastern and South-Eastern Europe and Central Asia (15 countries[4]), Latin America and the Caribbean and the Asia Pacific (results pending for the latter two regions);
- Global internet/list serve call for input: Dissemination of a brief questionnaire through ICASO's and UNAIDS' mailing list of community sector contacts, including more than 10 regional and global list-serves.

Key findings on community sector involvement

Identifying community sector members

8. In general, the ICASO supported reviews showed that no specific approach was developed for identifying who was in the 'community sector', by the sector itself or others, in order to be able to assess what groups to involve in the target setting process, particularly those representing the most affected.[5]

9. In a number of countries, the target setting process highlighted on-going tensions around the lack of a clear definition, particularly self-definition, of the community sector. In particular, it showed how the term can be used to encompass not only NGOs/CBOs, but multi-sectoral District AIDS Committees and Quasi-Government Organizations.

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[3] Algeria, Botswana, Central Africa Republic, Cote D'Ivoire, Gabon, Ethiopia, Kenya, Mali, Mauritania, Morocco, Nigeria, Rwanda, and Senegal.

[4] Albania, Armenia, Belarus, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, FYR Macedonia, Moldova, Montenegro, Romania, Russian Federation, Serbia, Tajikistan, Ukraine, Uzbekistan.

[5] ICASO has defines the community sector 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". ICASO, AfriCASO, and the Alliance, *Coordinating with Communities: Guidelines on the Involvement of the Community Sector in the Coordination of National AIDS Responses".* (May 2007).

Selection of community sector representatives

10. In most countries, community representatives were fully or partially selected by other sectors - notably government and UN – rather than their own constituencies. In many countries, existing membership of the CCM and/or the National AIDS Council (NAC) served as an entry point to - or 'de facto qualification' for - representation in the target setting process.

11. After some type of pre-selection process, representatives were sometimes either formally selected or confirmed by the community sector itself. For example, in Morocco, they were selected by the General Assembly of Community-based Organizations. However, more commonly, including in the 15 countries researched in Eastern and South-Eastern Europe and Central Asia, representatives were not officially endorsed by their constituents.

12. It was raised that in some instances the community sector representatives did not "represent" the views of key populations but rather that of their own organizations.

13. In most of the countries reviewed, the organizations that represented communities were the 'traditional' leaders of the sector, such as national networks or umbrella organizations of NGOs and people living with HIV. In many other African countries (including those with larger epidemics and multiple community stakeholders) only large-scale umbrella organizations were selected. In some countries, the combined representation of the community sector added up to a good cross-section of organizations and expertise.

14. In some instances, the lack of control by the community sector, transparency, and agreed criteria for the selection of community sector representatives caused tension. In other contexts, there was an observed lack of proactive action by communities to ensure their own representation, reflecting a lack of available information and resources to engage and coordinate.

Level of community sector involvement

15. In all of the countries reviewed, the community sector had some level of involvement in the process of target setting for universal access. However, the extent of that involvement varied significantly, in particular the involvement of key populations.

16. Across the countries reviewed in Africa, the community sector was not involved in the initiation of the process, only being called upon to participate once a list of targets had already been drafted. Meanwhile, in Kazakhstan, while community sector representatives were invited to an initial consultation (including to review the previous National AIDS Program), they did not participate in the identification of targets and the formulation of a new program.

> *"State structures are not motivated to involve civil society or they forget to do so."*
>
> Eastern European NGO

17. In Ghana, for example, the opposite scenario occurred. While the sector was not involved in the initial process that developed a 'road map' for universal access, it used its membership of the UNAIDS Technical Working Group to proactively advocate for community sector involvement. As a result, 12 organizations were invited to a national consultation meeting to validate the draft targets. This situation prompted the creation

of a task team to review the National Universal Access targets already set and perhaps re-open the consultation process.

18. Kenya provided a good example of other aspects of involvement, where the community sector was given adequate advance notice of meetings, with follow-up to confirm its attendance. Also, during meetings, the sector was given time to share its experiences in focus group discussions, while the plenary sessions were chaired by each sector in turn.

> *"There is a need to consult before starting the process, rather than just asking the community sector to validate an already designed set of targets"*
>
> Africa Universal Access Review Report, AfriCASO

Involvement of key populations

19. Beyond documenting the 'general' community sector involvement, the ICASO-supported review identified specific problems in attaining full and active involvement of people living with HIV and key populations in the target setting process. Lack of direct representation was seen in particular for sex workers, injecting drug users (IDUs) and men who have sex with men (MSM).

> *"Meaningful involvement of people living with HIV is not just about having the virus in the room"*
>
> Russian activist

20. Although this issue arose across the regions, they were particularly highlighted in the reports received from Eastern and South-Eastern Europe and Central Asia. For example, in Kyrgyzstan, Russia (see text box 2), Tajikistan and Ukraine, respondents mentioned that organizations working with key populations were involved in the process. However, in some countries, they also noted that actual members of key populations, such as IDUs, were not directly involved. Similarly, in Romania, although there is general acceptance within the country that the voice of those most affected by or vulnerable to HIV and AIDS should be heard, the participation of some key populations was minimal or non-existent.

Text box 2: Involvement of community sector and people living with HIV in Russia
Summary of the process and main challenges

The invitation to the community sector, and PLHIV groups in particular, to participate in a national consultation in December 2005 came at the last minute and the representatives were not briefed on the process. Despite this, UNAIDS and the Ministry of Health profiled the meeting as "involving" the community sector and people living with HIV.

Subsequently, the NGO Forum, the Russian Harm Reduction Network and the Russian Union of People Living with HIV convened a Working Group to review the proposed targets, recommended revisions and proposed its own targets, based on a needs analysis. In some cases, the Working Group refined the Federal AIDS Center (FAC) indicators based on suggestions in UNAIDS guidelines to make them more meaningful or measurable. It also suggested specific indicators on access to services for key populations.

After the Working Group had reached consensus on its suggestions, the indicators were sent to the email list serves of the three national networks – to gain input and legitimacy. The Working Group incorporated the feedback and sent its proposal to the FAC which, in turn, expressed its appreciation for the contribution of the community sector.

From this point on the community sector was not kept informed about the status of the targets, nor were any follow-up meetings held to create consensus. It was reported that ultimately the FAC selected the national targets. It excluded the targets that specifically addressed the needs of key populations, while keeping vague indicators on coverage of key populations through HIV prevention.

21. In many countries the meaningful involvement of key populations was limited by the continued lack of support for networking, skills development and resources to represent their community effectively.

Community sector representatives' consultations with their constituencies

22. In some countries, those representing the community sector made proactive efforts to consult with and report back to their wider constituency during the target setting process for universal access. However, in other countries little, if any, consultation was undertaken. The reasons cited for this included the tight timeframe for the national process and, in particular, the limited communications and decision-making infrastructure within the community sector.

23. Respondents in Africa reported two main strategies to inform or secure input from the wider community sector. These were data collection and analysis of community-based organizations' reports and interactive meetings among the community sector. In some countries, such strategies were supported by other stakeholders.

24. In a number of the countries reviewed, members of NGOs/CBOs from the sub national level were not directly represented or consulted, nor were key populations (IDUs, MSM and sex workers). Both groupings had little information about the process and, in turn, felt little ownership of the resulting targets.

Support for community sector involvement

25. In many of the countries reviewed the community sector lacked support – particularly financial and technical - for its involvement in target setting. In several other countries, however, respondents noted that their government and, in particular, UNAIDS played an important role in supporting the involvement of the community sector within target setting. For example, in Botswana UNAIDS provided guidelines and recruited a consultant to advise all stakeholders during the process and to convene a session with the community sector to verify the targets. The government and the African Comprehensive HIV/AIDS Partnerships also provided funding for the community sector to participate in the target setting consultations.

26. In countries in Eastern and South-Eastern Europe and Central Asia, it was particularly highlighted how UNAIDS played a vital 'third party' role – both giving the community sector direct opportunities for input and facilitating dialogue between the sector and government institutions. In this region, UNAIDS often also provided the community sector with financial and technical support. For example, in Belarus, before reviewing the national targets, the community sector was invited to talks on the process of establishing targets for universal access and the principles of monitoring key indicators for universal access. Meanwhile, in Ukraine, donors provided funding for large national consultations and provincial meetings to ensure the participation of a broad range of civil society constituents.

27. It was noted that global guidelines (by UNAIDS and the Global Fund for example) – that increasingly emphasize and, often, mandate multi-sectoral involvement – provided an important tool to advocate for the involvement of the community sector within the framework of universal access.

Impact on targets of community sector involvement

28. Across the countries and regions, examples of the benefits of the involvement of the community sector in target setting were identified as:

- *Providing a stronger understanding of the reality of AIDS* (Gabon).
- *Identifying priority communities in need of support, including those previously neglected* (Nepal).
- *Promoting the prioritization of key populations* (Algeria).
- *Developing highly specific indicators.* For example, in some Eastern and South-Eastern Europe and Central Asia countries, it was often community sector representatives who suggested looking specifically at behavioral indicators (such as the use of condoms and clean needles) for HIV prevention rather than using vaguer wording on access to services.
- *Overcoming cultural taboos*, for example about discussing the needs of key populations (Cote D'Ivoire).
- *Promoting a sense of urgency,* in terms of scaling up the national response to HIV and AIDS (Romania).

29. Where key population representatives were included, they brought more innovative and rights-based thinking to the table, based on their unique knowledge of the needs of their communities. In particular they *promoted 'unpopular' or 'political difficult' approaches* (see Text box 3).

Text box 3: Benefits of community sector involvement in Romania

In Romania, the representatives of the community sector brought a unique perspective to the target setting process – the voices of those directly affected by HIV and on the frontline of the epidemic – as well as their practical experiences of 'what works / what doesn't work' in programming. They also provided particularly valuable input into the setting of comprehensive and ambitious indicators for key populations. For example, the sector:

- Encouraged targets for IDUs to refer to services that include access to needle exchange, substitution treatment and other drug treatments, including within prisons.
- Advocated for the target for HIV tests for key populations to be increased from 1,199 in 2005 to 6,000 at the end of 2007.
- Promoted the inclusion of counseling, continuing education and life skills within the targets relating to people living with HIV.

30. However, in a number of countries, a distinction was made between the community sector's success in raising issues and its impact on the final targets. For example, again in Ghana, the sector brought attention to a number of issues, such as the importance of services, including ART, being free. However, although the sector's views were listened to, they did not change the actual targets.

31. In some countries, such as Botswana and the Central African Republic, the impact of the involvement of the community sector was felt to be weak and/or not very positive. This, in part, was felt to be a reflection of the legal situation and status of the community sector in the countries. Similarly, in countries in the Balkans – where, with the exception of Romania, participation was restricted to one-off national consultations – the community sector was also felt to have had little impact on the final sets of targets.

Community sector analysis of the targets set for universal access

Lack of ambition to reach universal access

> *"(We) commit ourselves to setting, in 2006….ambitious national targets"*
>
> The Political Declaration on HIV/AIDS, 2006
> Paragraph 49.

32. In many countries, the universal access target setting process appeared to be more an exercise for planning or expanding national AIDS plans, than setting ambitious targets. This seemed to stem from a lack of clarity in what is meant by universal access.

33. In particular, the exclusion of certain key populations and the setting of un-ambitious targets, hidden behind the term "realistic", was undertaken within a framework labeled "universal access". This undermines the broadly understood and used concept of "universal access" being about the ability of all people to have equal access to the quality services or commodities that they need to meet their HIV prevention, treatment, care and support needs.

Limited linkages with the UNGASS Declaration of Commitment on HIV/AIDS (DoC) targets

34. Across the regions, respondents noted that the link between the targets for universal access and those for the DoC depended on participants' engagement in both initiatives. In some countries, there was little widespread knowledge about either process and, as such, minimal understanding of the links between them. In some countries (Algeria, Ghana, and Nepal), the targets relating to the DoC served as a 'starting point' and guide for those for universal access.

Missing targets

35. The target setting process in many countries leaned heavily on existing documentation, such as National AIDS Strategies and country proposals for the Global Fund. In turn, this meant that the quality of the information used for the target setting process depended on the quality of the baseline data used for those previous or parallel processes.

36. The lack of accurate baseline information made it difficult to assess whether the targets were inclusive, balanced or responsive to the priority needs within the country. There was concern that the target setting process risked being based on 'informed guesstimates' rather than solid evidence. In many countries, there was a lack of disaggregated data, particularly in relation to key populations, to help determine whether the targets reflected the national priorities.

37. Consequently, across the countries reviewed, there a numerous gaps in the analysis and subsequent targets set for universal access that were of concern to the community sector informants to the ICASO-supported reviews. Examples include:

Comprehensiveness of interventions and targets	Targets set for specific key populations often failed to include the minimal or essential package of interventions. For example, in Russia, where there are high levels of HIV among IDUs and increasingly their sexual partners, behavior indicators were not set and targets were not inclusive of condom use, safer injecting practices or overall uptake of harm reduction services.

Human rights	In numerous countries reviewed in Africa, human rights related targets were missing or restrictive legislation was still in place that undermined other targets. None of the countries in Eastern and South-Eastern Europe and Central Asia included indicators on reviewing legislation related to key populations, and only four had targets related to human rights.
Equity of access	There is a lack of disaggregation of data, and consequently the targets, by gender, age, and key populations (e.g. sex workers, MSM,). Targets that show the degree of equity of access to services are mainly only available for prevention services, and they are often still not sufficiently disaggregated.
Human resources	Across the regions, there were insufficient targets set on addressing human resources gaps that are critically needed to rapidly scale-up responses, especially in Africa. In Eastern and South-Eastern Europe and Central Asia only one country reviewed had an indicator for human resources.
Opportunistic infections	Very few countries included targets related to treatment for opportunistic infections.
HIV-TB co-infection	Very few countries included targets related to HIV-TB co-infection.
National financial commitment and implementation strategies	In many of the countries targets were missing on the allocation of national funding on HIV/AIDS and mechanism for implementing the (ambitious) targets set.

Conclusions

38. While many of the experiences and issues raised in the reviews are specific to local contexts, epidemiological situations, and the level of development of the community sector, some key conclusions can be made from this review.

39. A lack of clarity and direction in what is meant by universal access has resulted in targets that are far from ambitious in many countries. Targets need to be set that seek to deliver on the goal of universal access and not remain some distant ideal notion, nor a slow incremental expansion of a national AIDS program. It requires a deeper understanding of the barriers to achieving equal access and of who needs what services and commodities within specific epidemics. Moreover, it needs a significant increase in the financial commitment by governments and donors to fund universal access that stays true to the ambitions and the lives of people living with and affected by HIV and AIDS.

40. To date, in countries where participation has been facilitated and supported, the impact of the involvement of the community sector in the process of target setting has been positive. The many benefits have included targets that are more evidence-based, focused on quality and responsive to key populations. UNAIDS has had a vital role to play as a facilitator in the process of target setting, in particular bringing different stakeholders together, particularly in contexts where government/ community relations are difficult.

41. In many countries, the process of involving the community sector has encountered significant barriers – in relation to attitudes, methods, resources, and logistics, amongst others (summarized in Annex A). These, in particular, have affected the involvement of people living with HIV and key populations.

42. The target setting process has highlighted many on-going challenges within the community sector, especially for key populations, including people living with HIV. In particular, it demonstrated the need for sustainable financial and technical support to strengthen communications infrastructures and build transparent and effective systems of representation.

43. The absence of adequate, disaggregated and high quality baseline data has posed a major challenge to the setting of valid targets across countries and regions. This especially applies to key populations – for whom baselines are often weak or non existent. This situation, in turn, has strongly highlighted the need for an agreed national Monitoring and Evaluation System as central to tracking the reality of the HIV epidemic and assessing any progress made on the targets set.

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Annex A

Factors facilitating and hindering the participation of the community sector	
Factors facilitating involvement	**Factors hindering involvement**
✓ Using a model of consensus-building – putting sectoral differences aside for the sake of the country's response to AIDS (Ghana). ✓ UNAIDS acting as a 'third party' and setting up opportunities for dialogue between the community sector and government (Belarus). ✓ UNAIDS providing the community sector with financial and/or technical support (Eastern and South-Eastern Europe and Central Asia). ✓ International donors providing financial support for community sector consultations and provincial meetings (Ukraine). ✓ Briefings being given to help the community sector understand the principles and process of target setting (Belarus). ✓ Use of participatory methods in national consultations, plus opportunities for each sector to chair plenary sessions (Kenya). ✓ The existence of strong community sector networks with good communications infrastructure – to facilitate involvement and build consensus (Russia and Ukraine). ✓ The community sector taking the initiative to assert its right to be involved (Ghana). ✓ 'Horizontal' communication between representatives of the community sector (Russia and Ukraine). ✓ The allocation of time within large community sector events to specifically discuss universal access (Eastern and South-Eastern Europe and Central Asia). ✓ Lessons learned from other national, multi-sectoral initiatives, such as the NAC and Global Fund (Senegal and Eastern and South-Eastern Europe and Central Asia). ✓ Guidelines for involvement being distributed to community networks (Botswana). ✓ Good administration and a realistic timeframe for the target setting process, including adequate notice of meetings (Kenya). ✓ Eagerness of key stakeholders, such as the NAC, to involve the community sector (Mauritania).	✗ A 'top-down' approach where the community sector is asked to validate pre-designed targets (Senegal). ✗ Centralized consultation processes, with a lack of opportunities for input from district-level stakeholders (Ghana). ✗ Logistics, such as holding meetings on week days when community leaders have to work (Belize). ✗ The overly technical nature of the national consultations – making them beyond the reach of some community stakeholders (Belize). ✗ A lack of coordination among the community sector, whereby: *"The NGOs were not organized enough to make their voice heard."* (Bosnia) ✗ *"Ever present fear of being discriminated against"* for people living with HIV and key populations (Belize). ✗ Lack of technical support to enable community sector representatives to understand the importance of / good practice for setting national targets (Eastern and South-Eastern Europe and Central Asia). ✗ Lack of understanding among community sector representatives of the concept and obligations of representation (Belize). ✗ Lack of coordination and information provision among the community sector (Central African Republic, Ethiopia, Morocco and Nigeria). ✗ The selection of community sector representatives being led by others (Nigeria). ✗ Lack of understanding by others of the culture and structures of community sector decision-making (Ethiopia). ✗ Use of languages that are not the first – language of the country or easily understood (Botswana). ✗ Tight deadlines and unrealistic timeframe for process (Cote D'Ivoire).