Initial Comments of the UNAIDS Reference Group on HIV and Human Rights on the UNAIDS/WHO Policy Statement on HIV Testing

Comments submitted to UNAIDS on behalf of the Reference Group – April 9, 2006

Attached please find the initial comments of the members of the UNAIDS Secretariat Reference Group on HIV and Human Rights on the UNAIDS/WHO Policy Statement on HIV Testing. As none of us were fully comfortable with the statement in its current form, we welcome the move towards revision.

As requested, below we provide comments on areas not included in the statement which we believe ought to be, as well as existing sections of the statement we believe ought to be revised. Although requested of us, we have not included suggested text. If of use, in this respect please refer to the summary guidance note provided in early 2004 prior to the drafting of the statement currently under review. Before spending time drafting language this time around it would be important to have clarity on the process for revision and how UNAIDS envisions the revised text would be used.

We provide these initial comments in written form but ask that sufficient time for discussion, and further input from group members, be ensured at our meeting and respectfully request assurances that a mechanism be put in place to ensure our ability to provide collective comments and suggestions as the process of revision moves forward.

The Reference Group remains committed to engaging with you further on testing and we look forward to discussion at the meeting. In the interim please let me know if further clarification on any of the points below is needed.

Best wishes,

General Comments

1. The current policy statement asserts that a human rights approach is needed for scaling up of testing. However, as a whole the statement does not employ human rights principles in how the issues are conceptualized and laid out. As the policy statement is not really based in human rights, even as it claims to be, we fear that this may be confusing for countries, settings and providers. In the current structure, the box at the end is disconnected from the statement. We would recommend, at a minimum, that the box be integrated into the text and that the 5 points in the box each be explained in such a way that they provide policy guidance. The point needs to be clear that scaling up must occur in each of these categories simultaneously. Consideration of testing policies in isolation will not be sufficient to ensure that more people know their HIV status, change their behavior, and get the care and support they need. We ask that these 5 points be included within the larger policy guidance, rather than simply appended as an add-on to the policy.

2. The title of the current policy statement is general enough that it appears to indicate that it is about HIV testing in all of its forms. Some explicit attention to the different settings in which testing
occurs as well as the different purposes for which testing is done would seem to be required. The statement is mostly about HIV testing within health care services, but not exclusively. Even within health services, the differences between VCT sites, generalized medical services and specialized clinics such as those that provide antenatal care and family planning must at a minimum be better clarified. The section laying out the 4 types of testing conflates many different types of testing and issues and is unclear. In addition, many environments where testing takes place are missing (e.g. prison, employment).

3. With respect to the above, it would also seem important to note the potential misuses of HIV testing. These include testing being used as a condition for employment, access to education, marriage, social benefits, access to health services, entering or staying in a country, etc. Given the resurgence of testing policies for reasons unconnected to access to ART (e.g. marriage, university entrance etc…), some attention to these uses of testing and to their inappropriateness would seem to be called for.

4. It would seem important to note that even as scaling up HIV-Testing is crucial in the context of prevention and access to ARV, one also has to consider that this increase in HIV testing may also lead to increases in stigma and discrimination unless handled appropriately. Additionally, perhaps a short explanation on the causes of stigma and discrimination and how they manifest both in how testing is done and how the results may be used could usefully be added.

5. It would seem that VCT (the fact that testing should be voluntary and that some form of counseling should exist) is key whether or not the testing is provider-initiated or client-initiated. We would recommend making this point clearly and altering the structure of the paper so that VCT is not only the title for the section on client-initiated testing but would permeate as a concept throughout. Using the words “voluntary” and “confidential” at the beginning of the text would be important to set the tone but it would also seem important to use the language of VCT throughout to make it clear that these principles are key whether testing is initiated by the client or the provider and in all relevant circumstances.

6. The word availability is used throughout the text in relation to treatment but it would seem important to clarify that in addition to being available treatment must also be accessible, acceptable to the community and that if the testing policy is based on the availability of treatment, whether ART or treatment for OIs, that this will need to be sustainable.

7. The policy needs to provide some specific guidance as to the differences in populations intended to access testing and impacted by testing policies. This includes legal, policy as well as community norms which limit the access of certain members of the population either to testing or to the benefits of testing such as on the basis of age and gender. The impact of testing on stigmatized and discriminated-against populations should also be given explicit consideration in relation to the specific requirements and practices of the testing process itself, including informed consent and confidentiality, as well as the health and social consequences of a positive test result.

8. As the document is revised, it will be critical for it to be reviewed for clarity with attention to how it will be interpreted and used due to the political and economic realities existing within countries. This means recognizing and addressing the potential misuse and potential violations of rights which might take place because of the lack of clarity within the policy as to how it can and should be implemented (in what circumstances and in what ways..) particularly when resources are limited.

Some specific comments:
9. Par 2. As written it is not clear if people don’t access the services because they are not available, because the people don’t know about them, they are not interested, or they do not care.
10. Par 3. We would suggest addition of the word "effective" when noting stigma and discrimination protections, as well as the need for redress mechanisms that people know about and can access.

11. Par 3. While the need for integrated services as noted is clear, just to state the obvious it is not possible to integrate services that do not exist. And in places where they are just beginning, certainly one does not need to wait for all of them to be in place prior to integration. In addition to suggesting integration for places where this is possible as is done in the current draft, therefore, the addition of language noting the need to "simultaneously scale up services" or something similar might be useful.

12. Par 3. In addition to noting the needs of young people, vulnerable populations generally (youth, women, sex workers, people who inject drugs, migrants, etc) all need to have access to "friendly" services, designed to meet their needs.

13. Par 4. The statement talks about the primary model for HIV testing being client-initiated etc. However, while this may be true with respect to health services it contributes to the confusion within the text as to whether the text is about health services or testing more broadly.

14. Par 4. The policy also needs to be much clearer than what exists in the current draft in suggesting that provider-initiated testing requires that the provision of, or referral to, effective prevention and treatment services is assured. Many of the problems are because providers are offering/imposing testing even if prevention, treatment and care are not available, let alone accessible and the statement does not offer sufficient guidance on this point.

15. Finally, the section on mandatory HIV screening is contradictory and not clear. The ways in which pre and post test counseling are relevant needs to be clarified, and the specifics of different circumstances better articulated. In addition, some stronger statement against testing being done in conjunction with immigration may be warranted given the UNAIDS/ IOM statement etc.

Additional comments received from members after April 9, 2006

16. The AIDS and Rights Alliance of Southern Africa (ARASA) recently held a SADC regional consultation on HIV testing - a draft consensus statement will soon be ready.

17. There is a lack of hard data about what is happening with HIV testing, certainly in sub-Saharan Africa. There is no systematic monitoring of VCT, budgets, sites where there is routine offer, policy, outcomes etc. Research is needed in this area to guide policy and program guidance into the future.

18. HIV tests have been misused and it is important for the statement to clarify this point. They can effectively be used for prevention, diagnosis, and clinical purposes leading to care and treatment. In some places, public health is used as a justification for compulsory interventions so the assertion of the need to ground testing in human rights is critical to ensure this does not happen.

19. The reference to diagnosis of HIV in the context of TB is again (deliberately?) vague and possibly misleading. The statement can be interpreted as recommending systematic HIV testing as part of "routine diagnosis", thereby making it "mandatory". There is no reason for making this test mandatory. Empirical evidence is accumulating supporting that informed consent prior to HIV test is not a deterrent to the acceptance of dual testing and good treatment, but in fact just the opposite. HIV Testing in TB patients has to be voluntary and associated with counseling.

20. Regarding the last paragraph in the current statement (testing of the military): two reasons are usually given for this testing: fitness for duty and liability. The first is commented on, not the latter which in fact raises the broader issue of mandatory testing for access to health/life insurance (not addressed in the document). An added statement could address this issue along the following lines: UNAIDS/WHO do not recommend the mandatory HIV testing of applicants for health or life insurance as it defeats the purpose of establishing solidarity in risk management. When such
practices are performed, they must be subjected to informed consent and pre and post test counseling. Results of the test should be protected by medical secrecy with no specific reference to HIV being made by medical examiners when formulating their recommendations.

Questions for Discussion

1) In addition to the comments submitted above, what additional issues do Reference Group members believe should be included in any revised HIV testing policy?

2) What is the mechanism to be put in place to ensure the Reference Group’s ability to provide collective comments and suggestions, and ensure their integration as the process of revision moves forward?

This issue paper was prepared by the Reference Group Secretariat to facilitate discussion at the Reference Group’s April 2006 meeting.