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OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS AND UNAIDS

INTERNATIONAL EXPERT CONSULTATION

ADVANCING CARE, TREATMENT AND SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS: UPDATING GUIDELINE 6 OF THE INTERNATIONAL GUIDELINES ON HIV/AIDS AND HUMAN RIGHTS

GENEVA, 26 JULY 2002

CONCLUSION OF THE THIRD INTERNATIONAL CONSULTATION

The Hon Justice Michael Kirby AC CMG
(Australia)

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THE THIRD CONSULTATION

The rapid spread of HIV/AIDS throughout the world has brought with it death and suffering to many millions. It has also been accompanied by stigma and discrimination - in part because of the common vectors of transmission (including sexual intercourse and injecting drug use) and in part because, until recently, there has been no effective treatment.

In these circumstances, it was unsurprising that the United Nations Commission on Human Rights should, in the 1990s, address its attention to the promotion and protection of respect for human rights in the context of the HIV/AIDS epidemic. In response to a first international consultation on AIDS and human rights, convened by the then United

Nations Centre for Human Rights and the World Health Organisation (HR/Pub/90/1), a second consultation was convened by the High Commissioner for Human Rights ("the High Commissioner") and UNAIDS in September 1996. By that time each of these offices had assumed leadership roles in respect of the coordination of United Nations activities with respect to human rights and the response to HIV/AIDS.

The second consultation agreed on international guidelines. These were published jointly by the sponsoring organisations in 1998: *HIV/AIDS and Human Rights - International Guidelines* (HR/Pub/98/1). They have been republished many times. They have been considered and welcomed by many organs of the United Nations. They were before the United Nations General Assembly Special Session on HIV/AIDS in June 2001.

The sixth guideline addressed the obligation of States to institute preventive measures and to provide services in response to the epidemic. Specifically, that guideline calls on States to enact legislation to ensure the availability of prevention measures and services, care, information and safe and effective medication at an affordable price. However, in numerous meetings since 1996, the imperfections of Guideline 6 have been called to notice. The imperfections identified include:

* The suggestion that the proper response to the provision of effective medication is to be viewed only, or primarily, in the context of prevention measures;
* The suggestion that the provision of medication should be considered only, or primarily, in the context of legislative measures; and
* The appreciation of the rapid advance in the availability of diagnostic tests and treatments effective to help prevent, or significantly delay, the onset of AIDS and of opportunistic conditions leading to death as well as to improve greatly the quality of life of those having access to such treatments. Foremost amongst these have been the anti-retroviral therapies that, substantially, have become available since 1996.

In many developed countries, with effective national health systems or providing access to private insurance or with populations typically enjoying larger individual means, the availability of these advanced forms of diagnostic tests, medications and other treatments will commonly be feasible and often as a matter of legal right, at least to the citizens of those countries. However, in many, indeed most, countries of the world, access to such treatment and care is presently impossible for the vast majority of persons living with HIV/AIDS.

It was these contextual considerations, and the international debate which they have engendered concerning the obligations and requirements of the international law of human rights that persuaded the

High Commissioner and the Executive Director of UNAIDS to convene a third consultation in Geneva on 25-26 July 2002.

Some of the participants in the third consultation had been present at one or both of the previous consultations. The mandate of the third consultation did not extend to a general review of the international guidelines. It was limited to the consideration of any updating of Guideline 6 that was suggested by changes that had occurred since that guideline was adopted in 1996.

The third consultation was provided with leadership and support from each of the sponsoring bodies. Ms Marika Fahlen (Director, Department of Social Mobilisation and Information, UNAIDS) was present throughout the meeting as was Ms Miriam Maluwa of UNAIDS. Ms Stephanie Grant (Chief, Research and Right to Development Branch of the Office of the High Commissioner for Human Rights) led the participants provided by the High Commissioner to assist in the work of the consultation. Those participants included Ms Lisa Oldring and Mr Simon Walker, to all of whom the international experts are indebted.

The rapporteur elected by the third consultation was Mr Richard Elliott of the Canadian HIV/AIDS Legal Network. He prepared a background paper which accurately, and exhaustively, reviewed the history of the international guidelines and the many references to, and considerations of, their provisions, specifically relevant to Guideline 6, since their adoption in 1996. The international experts paid tribute to Mr

Elliott not only for his paper but for his outstanding work during the consultation in responding to the questions, comments and suggestions of the participants.

The third consultation worked exhaustively over two days. There was a vigorous exchange of diverse points of view. In the end, there was consensus about the recommendations that should be made to the sponsoring organisations. As chairperson of the third consultation, I pay tribute to all participants in the consultation. They approached their functions with integrity and with a full realisation of the significance which the challenge of HIV/AIDS presents to the international community and, specifically, to the principles of that community obliging respect for the human rights and human dignity of all people everywhere.

APPLICABLE HUMAN RIGHTS NORMS

A threshold question arose soon after the opening of the meeting. It followed consideration of the rapporteur's background paper. Specifically, it was presented by the numerous reports in that paper of the deliberations of international agencies of the United Nations concerning the international guidelines and their contents.

The issue concerned the extent to which it could be said that, as a matter of international law, the commitments of individual member states of the United Nations, the provisions of binding treaties sponsored by the United Nations, the resolutions of the governing bodies of the United

Nations and of its several agencies and the opinions of international writers warrant a conclusion that international law has now advanced to the point of imposing on member states an affirmative obligation to provide access to diagnostic tests, medications and other care or the treatment of HIV/AIDS and of the opportunistic conditions to which HIV/AIDS renders those infected susceptible.

The issue of the extent to which, and manner by which, so-called "soft law" developments in the agencies of the United Nations can accumulate and contribute to the imposition of "hard law" duties in the nature of norms or principles of binding international law is one upon which there is much international debate and controversy. The participants in the consultation reviewed carefully the detailed analysis of the rapporteur concerning developments that had occurred in international law since the international guidelines were adopted in 1996 - and in particular the express references to those guidelines by the General Assembly of the United Nations, the Commission on Human Rights, other agencies, regional bodies and the courts of member states. Various views were expressed both as to the principle that was applicable and as to its application to the particular question of the obligation to provide access to now available treatments (especially anti-retroviral therapy) as a matter of binding law, grounded in the obligations of internationally respected human rights.

Whilst the international experts were generally of the opinion that the developments in the exposition of an international consensus

achieved since 1996, together with regional and municipal developments, pointed towards the direction of the imposition of binding universal, international obligations to make available to persons infected with HIV life-saving and highly beneficial treatments now available, they could not agree that a universal general rule obliging the provision of such medications, diagnostic tests and other therapies had yet become a universal binding rule of the international law of human rights.

Based on the materials in the background paper and other developments, many of the international experts were of the opinion that such a development was in the course of emerging. Most of the international experts felt that such a legal norm would in due course arise from the developments already in train. Most recognised that the profound impact that currently available therapies had upon the saving of human life, the extension of human existence and dignity and the saving of pain, suffering and discrimination. These factors combined to make it likely that such a rule would emerge and be recognised by the international community as part of universal international law. The inadmissibility of differentiating amongst human beings in respect of access to such a profoundly beneficial and indeed life-saving treatment, depending upon the country of birth, citizenship or residence or accidental features such as private wealth or insurance, convinced many of the international experts that a deep moral obligation was invoked. This would, in due course, be reflected amongst the norms of the international law of human rights grounded in such basic notions as the

right to life, to respect for human dignity, a right to health measures and otherwise.

Nevertheless, having regard to the current state of international law, emerging inter alia from the consideration of the international guidelines and other developments since 1996, the experts could not conclude affirmatively that a universal norm had already emerged. They believed that the background paper should reflect this general opinion. However, they did not consider that this conclusion was determinative of the task with which they were mandated in the present consultation. The expression of international guidelines was not governed only by the norms of binding international law. It was appropriate to include in such international guidelines emerging rules that amounted to best practice in the international community. On this footing, there was no doubt that best practice supported the provision, not only by legislation but also by other means, of assuring rights of access of those infected with HIV to available medications, therapies , tests and other care and attention that would save life and reduce suffering, stigma and discrimination that were a consequence of the failure to provide access to such benefits.

The international experts recommended that the rapporteur should, in his revision of the background report, differentiate between those binding obligations that individual states may have accepted as governing their own conduct in respect of such matters and the current position so far as a universal principle of international human rights law was concerned.

REVISION OF GUIDELINE 6

Having concluded that this was the appropriate approach to its task, the consultation turned to the revision of Guideline 6. In the end, by consensus, the consultation agreed upon an alteration to the present title to Guideline 6 to reflect the larger emphasis in the revised guideline on the provision of treatment, and access to care and support. The consultation also agreed to add provisions to the prevent Guideline 6 to spell out, in greater detail, the emerging obligation that should find reflection in the international guidelines.

A threshold debate arose, in this respect, as to whether the present terms of Guideline 6 should be scrapped and reworded in their entirety so as to replace the current text.

In favour of such an approach was a feeling, shared by many of the international experts, that the original Guideline 6 gave undue attention to the access to "safe and effective medication at an affordable price" in the particular context of preventive measures. Many of the experts pointed out that access to such medications and other forms of treatment, care and support, represented separately justified entitlements, presented by the advances in available therapies, tests and so on. They were not restricted to the utility of such therapies etc as they advanced prevention of the spread of HIV. Some criticised the notion that the sole or principal focus of a human rights response to

HIV/AIDS should be upon prevention of further spread of the epidemic, as distinct from the achievement of that objective *together with* the assurance that the best of available treatment, care and support should be assured to those who were already infected with HIV.

There was also criticism of the notion, possibly suggested by the language of the present Guideline 6, that the focus of the obligation of states should be upon the enactment of legislation. Practical considerations such as the provision of medication might (and, in most states, would) depend not so much on legislation as upon the existence of an appropriate commitment by the government and authorities and the devotion of the necessary resources (or securing assistance from international sources) to ensure the availability of treatment, care and support as a matter of practice, not simply of law.

However, whilst acknowledging the force of these criticisms of the present Guideline 6, the participants agreed that it was preferable to add to the present Guideline rather than to delete its present text and start afresh. The reasons for this course were many. They included the undesirability of suggesting a general reopening of the Guidelines; the lack of a mandate in the consultation to go beyond Guideline 6; the many international references to and expressions of support for the present Guidelines (including the present Guideline 6) stated in various resolutions of the international agencies and elsewhere; and the desirability of delineating between legislative and other responses, each of which had a legitimate part to play.

It was on this footing that the participants agreed not to change the present Guideline 6 but to propose an addition to that guideline which would capture the new emphasis proposed by the consultation upon treatment, care and support. In this way, although the revised Guideline 6 would be somewhat more elaborate than the other Guidelines, it would leave the present text intact. By adding an additional paragraph, it would make clear the new emphasis being placed on practical treatment and care, having regard to the advances in the availability of methods of treatment, care and support since the international guidelines were adopted in 1996.

In addition to the alteration, adding a new paragraph to Guideline 6, the participants also agreed on a number of points that should be included in new subparagraphs to that guideline both to reflect the intended operation of the added paragraph of Guideline 6 and also to reflect the substantial debates that had occurred during the consultation on the issues which the revision had suggested.

The international experts were conscious of the desirability of securing the earliest possible adoption of the revised form of Guideline 6. In particular, the consultation was hopeful that it would prove possible for the present High Commissioner and the present Executive Director of UNAIDS to jointly endorse and distribute the international guidelines with the added text to Guideline 6 without delay.

To this end, the participants accepted the obligation, imposed by the consequent deadlines, to review the redraft of Guideline 6 and the subparagraphs, as recommended by the rapporteur within a week of the conclusion of the third consultation. It was felt important that the subparagraphs should explain the reasons that lay behind the need for a revision of Guideline 6. Most significantly, such considerations included the important advance in the availability of medications since 1996 (most especially anti-retroviral therapy) and the impact which, once provided to persons infected with HIV, such treatment, care and support would have upon the present burdens of stigma and discrimination. Once HIV/AIDS becomes, substantially, a treatable condition, like other illnesses, a significant part of the reason for discrimination and stigma fades away. At the very least, it is substantially diminished.

The participants in the consultation expressed the hope that, in his revision of the background document, the rapporteur would reflect the foregoing considerations. The participants expressed the wish that the background document, as providing a most useful source material, would be published in an appropriate way and thus available for the elaboration and understanding of the added terms proposed to Guideline 6.

DISSEMINATION AND FOLLOW UP

The participants in the third consultation then turned their attention to dissemination of the revised international guidelines, once approved.

They recommended that the revision should be provided by the co-sponsoring bodies to the Secretary-General, the relevant treaty bodies and the governments of member states (including Ministries of Justice, Health, Finance, Trade and International Development). The participants recommended that the revised international guidelines also be provided to networks of civil society and non-governmental organisations, including the International AIDS Society. Copy should also be sent to the International Red Cross and Red Crescent organisation. They expressed the hope that the revision would be made known to relevant United Nations agencies and in particular the Commission on Human Rights. They proposed that it be made available to the Commonwealth Secretariat and to regional human rights bodies as well to national AIDS commissions, national human rights commissions, ombudsmen and other office-holders with relevance to the HIV/AIDS epidemic.

Specially, the participants recommended that the guidelines be made available by the High Commissioner to the Special Rapporteurs on Human Rights of the United Nations and the Special Representatives of the Secretary-General with functions relevant to human rights. The appointment of a new Special Rapporteur on Health afforded a specific office-holder who could assume particular obligations in the follow-up of the international guidelines generally and specifically of the revised form of Guideline 6.

The participants expressed the hope that the international guidelines and the revision of Guideline 6 would be drawn to the notice of the incoming High Commissioner for Human Rights.

Numerous other suggestions were made for distribution. They included to the staff of the Global Fund; representatives of the pharmaceutical industry; the global business community; and regional political groupings such as ASEAN. It was proposed that the international guidelines and the revised Guideline 6 should be drawn to the notice of organisers of various international meetings with relevance to HIV/AIDS, including the regional conference in Latin America (April 2003) and the Asia-Pacific conference in Kobe, Japan (2003). It was also proposed that the provision of Guideline 6 be linked to the UNAIDS two year campaign against stigma and discrimination.

Specific recommendations were made to include the guidelines on the Websites of the sponsoring bodies. It was recommended that particular care be paid to the provision of the revised Guideline 6 to the media who can be an important ally in spreading knowledge of such advances in United Nations' consideration of such topics.

The participants recommended that in letters to member states of the United Nations specific proposals should be made concerning the action that it was hoped member states would take in response to the revised Guideline 6. Particular attention should be paid, in that regard, to the obligation of least developed states to seek international aid to

fulfil the commitment recognised in the revised Guideline 6. Otherwise, it would be too easy for many states simply to indicate that they could not afford the provision of the medications that can make such a profound difference to the lives and well being of persons living with HIV/AIDS.

The participants in the consultation differentiated between dissemination of the guidelines and their actual follow-up. They were of one voice in accepting that the adoption of another piece of paper in response to the HIV/AIDS epidemic was only useful as it promoted real change in practice, especially in developing countries. The object of the revision of Guideline 6 was not to secure a high sounding resolution. It was to ensure the actual provision of treatment, care and support to people living with HIV/AIDS who do not presently have access to such treatment, care and support and in particular anti-retroviral therapies.

The participants committed themselves to drawing the guidelines, if adopted by the sponsoring organisations, to the attention of their own governments and civil society organisations. They expressed the hope that the sponsoring organisations would commend the guidelines to the Commission on Human Rights and that that body would be offered a plan of action to ensure that the new Guideline 6 was implemented as a matter of practice.

CONCLUSION OF THE CONSULTATION

The conclusion of the consultation took place in the presence of the High Commissioner for Human Rights, Ms Mary Robinson.

The participants paid tribute to the High Commissioner for her concern about, and unflagging interest in, new issues of human rights at the cutting edge of that discipline. They also paid tribute to Dr Peter Piot, Executive Director of UNAIDS, for his clear sighted perception, from the earliest stages of the epidemic, of the inter-relationship of the protection of human rights and effective responses to the HIV/AIDS epidemic. They expressed their admiration for the cooperation between the sponsoring bodies and hoped that this would continue. They also expressed their consciousness of the high responsibility that they had shared in participating in the international expert consultation. They pledged themselves, if required, to provide further assistance in the future, as new medical, social and international developments made it useful or necessary to reconsider the revised *International Guidelines on HIV/AIDS and Human Rights.*