FOIA Number: 2007-1550-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member:

Subseries:

OA/ID Number: 19396

FolderID:

Folder Title:
Issues-Civil Rights 1996

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	5	3

ISSUES
Cavil Pts
1994

HIV series

Reproduced with permission of the publisher. Kirby M. Human Rights and the HIV Paradox. *Lancet* 1996; 348(9036):1217-1218.

Human rights and the HIV paradox

Michael Kirby

Faced with the grave challenge to public health posed by HIV infection, governments are obliged to "do something". One response, which often finds favour with the general public, is to enact laws that criminalise the activities of certain target groups. However, such laws marginalise individuals in these groups and have very little impact on containment of the epidemic. It is far better to introduce measures that protect the rights of people most at risk of infection and thereby encourage and sustain behaviour modification.

For centuries people like me have been sentencing and locking up other people in the social groups which are now most exposed to HIV infection—sex workers; homosexuals and bisexuals; drug users; adulterers; promiscuous people. The effort has been only partly successful. Resolutely, in their quest for pleasure and their pursuit of happiness, the targeted groups have often ignored social sanctions. They have defied the law and its punishments. They have run risks and largely gone on doing what they wanted. Some were deterred by the awful pronouncements of people in black robes. But most were not.

Behaviour modification is hard to achieve at the best of times. It is harder to sustain where people's pleasures are involved. This product of judicial experience teaches that we cannot place much store on law enforcement as an effective and immediate means of achieving behaviour modification to help contain a pandemic such as that involving HIV.

Yet as several articles in this series have revealed, the pace of developments in the search for a cure and a vaccine has been so disheartening that unprecedented attention is now being paid to behavioural and social change and how, in practice, to procure it. For the foreseeable future, these uncertain and imperfect strategies will be essential to effect HIV prevention programmes everywhere. Whilst in developed countries some progress has been made in HIV prevention by mobilising political commitment to saving lives and by taking courageous and controversial decisions (eg, syringe exchange), in most developing countries, which carry the greatest share of the global burden of the pandemic, the prospects of effective interventions often appear very bleak. They run headlong into deeply entrenched social phenomena such as:

- Religious and other impediments to the education of children in schools and colleges and in the media about sexual transmission
- Disempowerment of women, so that they cannot defend themselves against unprotected sex
- Prohibitions, by law and social convention, on homosexuals, on injecting drug users, and on sex workers
- Unavailability of affordable and suitable condoms
- Lack of clear political commitment to take the radical steps necessary to save lives.

Reflection on the current stage of the HIV pandemic, the progress, or lack of progress, towards really effective treatment and a vaccine, and the problematic nature of promoting and sustaining behaviour modification are enough to engender a feeling of despair and even desperation.

Against this background it is essential that we place the efforts of enlightened elements in the international community to respond effectively to the HIV pandemic in the context of universal human rights. This is not just theory. It is a matter of placing our debates in a conceptual and historical framework from which people in the know can seek to argue for action by people with power who are ignorant and often obstructive.

Although the international human rights movement has a long history, its global manifestations really only gathered pace after the terrible suffering and revelations that followed the Second World War. The *Universal Declaration of Human Rights* 1948 and the *International Covenants on Human Rights* 1966 incorporate fundamental principles, which are now part of international law. They uphold the dignity and entitlements of each human being on earth (panel 1).

Many citizens—and most political leaders—will question what human rights have to do with a successful strategy to contain the spread of HIV. It is here that the HIV paradox arises for consideration. However imperfect our understanding of the tools of behaviour modification, this much at least seems clear. To have a chance of penetrating into the mind of an individual, so that he or she secures the knowledge essential to change behaviour at a critical moment of pleasure-seeking, it is imperative to win the trust of that individual. Only in that way will their attention be captured in a manner that will convert words and information into action. Pamphlets and posters, homilies and sermons are only of minor use in this regard. What is needed is the direct supply of

Panel 1: Human rights

Rights to healthcare, which include preventive health education and self-protection

Rights to privacy (now held to extend to rights to sexual privacy and to one's sexual orientation)

Rights to shelter and housing

Rights to employment without discrimination

Rights of children to be given basic information necessary for their protection, health, and life

Rights of women to the dignity of their person and to protection from violence, including unconsensual sexual conduct

Rights to protection against oppressive laws and policies of the state

Lancet 1996; **348:** 1217–18

High Court of Australia, PO Box E435 Queen Victoria Terrace, Canberra, ACT, 2600, Australia (The Hon Michael Kirby AC CMG, President of the International Commission of Jurists; former member of the WHO Global Commission on AIDS; Justice of the High Court of Australia)

information by a source regarded as trusted, impartial, and well intentioned, so that, by repeated messages of this kind, a general awareness about the existence of HIV can be translated into individual daily conduct.

The paradox is that laws which criminalise particular target groups (sex workers, homosexuals, injecting drug users, &c) may appear to be a suitable response. They are often attractive to the public and therefore to distracted politicians who are anxious to be seen to be doing something in the face of the grave challenge to public health that HIV presents. But experience teaches that such responses have very little impact on the containment of an epidemic of this nature. They actually tend to have a negative impact on behaviour modification because they place target groups beyond the reach of the requisite information. They undermine the creation of the supportive social and economic environment in which effective strategies can be prosecuted.

Thus the HIV paradox teaches, curiously enough, that one of the best strategies of behaviour modification which will actually work to reduce the spread of HIV, by enhancing and sustaining self-protection, is to be found in measures that positively protect the target groups and uphold the rights of individuals within them. In those countries where there has been a measure of success in achieving and sustaining behaviour modification, and thereby reducing the spread of HIV infections, such strategies have been adopted (panel 2).

To those who find the HIV paradox unconvincing or even offensive, two answers may be given. The first is that of practicality. No other strategy has been shown to work. Without effective behaviour modification HIV will continue to spread rapidly, causing enormous personal suffering and devastating economic and human loss. By 1987, most informed health officials, led by the World Health Organization, had come to recognise the force of the HIV paradox. However, their endeavour to supplement public campaigns and health prevention efforts with attention to human rights has only been partly successful. The effort must continue.

The second justification for the strategy which I have described takes me back to fundamental human rights. They are important, not because they are contained in international instruments or national constitutions or laws. Their importance lies in the fact that such rights are basic for every human being for no reason other than the humanity and unique individuality of each one of us. I once explained, to a law school in the USA, the practical reasons for supporting a strategy protective of the rights of individuals specially at risk of HIV infection. A young law student rebuked the judge. He told me that I had forgotten the main reason. This was that we accord every human being that person's human rights because it is our duty and their right. When epidemics are about, human rights tend to go out of the window. But even in times of epidemic, departures from respect for fundamental human rights must be controlled by law. They must be limited to measures that are strictly proportional and necessary. They must be compatible with the other objectives of a democratic society.

Panel 2: Strategies to contain HIV infection

Introduction of systems for the exchange of sterile needles

Legalisation or decriminalisation of adult, consensual, private homosexual conduct where this has been illegal

Decriminalisation of prostitution and other activities of sex workers and legalisation of brothels

Facilitation of school education and public information in frank and direct terms, including by imaginative use of the public media

Publicity concerning condom use and the free distribution of condoms in selected venues

Involvement of representative community groups and leaders in programmes designed to sustain behaviour-modification campaigns

Provision of the best affordable medical care and up-to-date information to persons living with HIV

In the struggle against HIV/AIDS we need to learn again the lessons that were taught nearly a century ago when syphilis presented a major challenge to public health in some ways similar to that now presented by HIV. The manifestations of symptoms were delayed. The condition was often, ultimately, fatal. The drug therapy then available was incompetent and had serious side-effects. The social stigmas were substantial and they arose largely from the sexual modes of transmission. This was a time before advanced therapy. It was only when syphilis was treated in a way which accepted its reality, applied strategies to promote non-transmission, and respected the rights and dignity of the patient, that any real progress was made towards containment.

HIV shines the spotlight of human rights on medical practice, epidemic control, and our social responses to aspects of human sexuality and drug-taking. Only by re-learning the lessons of the past, and by studying such successful endeavours as exist in the present, will we avoid the mistakes that beset most of the present strategies against HIV. The problem is extremely urgent. The obstacles are many. The apathy, indifference, and hypocrisy that attend such terrible suffering are appalling. Teaching the HIV paradox to frightened communities is by no means easy. Yet we must persist in our attempts to do so.

Let me therefore lay it on the line: the most effective strategies we have so far found to help promote reduction of the spread of HIV involve the adoption of laws and policies which protect the rights of the people most at risk of infection. This may seem surprising. It *is* a paradox. But it is so. The appalling neglect and denial, especially in developing countries, should be reversed in their own economic interests and in the interests of the rights of their people. We should take this course because it is all that is likely, at this stage, to be effective in changing the behaviour we need most urgently to change. But we should also do it because it is right.

1996, 71, 289-296 No. 39

World th Organization, Geneva Organisat mondiale de la é, Genève

WEEKLY EPIDEMIOLOGICAL RECORD

RELEVE EPIDEMIOLOGIQUE HEBDOMADAIRE

27 SEPTEMBER 1996 • 71st YEAR 71e ANNÉE • 27 SEPTEMBRE 1996

Joint United Nations Programme on HIV/AIDS (UNAIDS). HIV and Infant Feeding: An Interim Statement. *Weekly Epidemiological Record* 1996; 71(39):289-291.

Joint United Nations Programme on HIV/AIDS (UNAIDS)[1]

HIV and infant feeding: An interim Statement

Introduction

The number of infants born with HIV infection is growing every day. The AIDS pandemic represents a tragic setback in the progress made on child welfare and survival.

Given the vital importance of breast milk and breast-feeding for child health, the increasing prevalence of HIV infection around the world, and the evidence of a risk of HIV transmission through breast-feeding, it is now crucial that policies be developed on HIV infection and infant feeding.

The following statement provides policy-makers with a number of key elements for the formulation of such policies.

The human rights perspective

All women and men, irrespective of their HIV status, have the right to determine the course of their reproductive life and health, and to have access to information and services that allow them to protect their own and their family's health. Where the welfare of children is concerned, decisions should be made that are in keeping with children's best interests.

These principles are derived from international human rights instruments, including the Universal Declaration of Human Rights (1948), the Convention on the Elimination of All Forms of Discrimination Against Women (1979), and the Convention on the Rights of the Child (1989), and they are consistent with the Cairo Declaration (1994) and the Beijing Platform for Action (1995).

[1] United Nations Children's Fund (UNICEF), United Nations Development Programme (UNDP), United Nations Population Fund (UNFPA), United Nations Educational, Scientific and Cultural Organization (UNESCO), World Health Organization (WHO), and World Bank.

Programme commun des Nations Unies sur le VIH/SIDA (ONUSIDA)[1]

VIH et alimentation du jeune enfant: Déclaration intérimaire

Introduction

Le nombre d'enfants qui naissent porteurs du VIH augmente chaque jour. La pandémie de SIDA compromet tragiquement les progrès réalisés dans le domaine de la survie et du bien-être de l'enfant.

Du fait de l'importance vitale du lait maternel et de l'allaitement au sein pour la santé de l'enfant, de la prévalence croissante de l'infection par le VIH dans le monde, et de l'existence d'un risque de transmission du VIH par l'allaitement au sein, il est désormais crucial d'établir des politiques concernant l'infection à VIH et l'alimentation du jeune enfant.

La présente déclaration vise à fournir aux décideurs certains éléments fondamentaux pour la formulation de telles politiques.

Une approche fondée sur les droits des personnes

Toutes les femmes et tous les hommes, quel que soit leur statut sérologique vis-à-vis de l'infection à VIH, ont le droit de déterminer le cours de leur vie et de leur santé reproductives, et le droit d'avoir accès aux informations et aux services qui leur permettent de protéger leur santé et celle de leur famille. Lorsque la santé et le bien-être de l'enfant sont en jeu, il convient de prendre des décisions protégeant au mieux les intérêts de l'enfant.

Ces principes découlent des documents internationaux relatifs aux droits des personnes, notamment la Déclaration Universelle des Droits de l'Homme (1948), la Convention sur l'Elimination de toutes les formes de Discrimination à l'Egard des Femmes (1979), et la Convention sur les Droits de l'Enfant (1989), et sont en accord avec la Déclaration du Caire (1994) et le Programme d'action de Pékin (1995).

[1] Fonds des Nations Unies pour l'Enfance (UNICEF), Programme des Nations Unies pour le Développement (PNUD), Fonds des Nations Unies pour la Population (FNUAP), Organisation des Nations Unies pour l'Education, la Science et la Culture (UNESCO), Organisation mondiale de la Santé (OMS), et Banque mondiale.

CONTENTS — SOMMAIRE

Preventing HIV infection in w

The vast majority of HIV-infected children have been infected through their mothers, most of whom have been infected through unprotected heterosexual intercourse. High priority therefore, now and in the long term, should be given to policies and programmes aimed at reducing women's vulnerability to HIV infection, especially their social and economic vulnerability – through improving their status in society. Immediate practical measures should include ensuring access to information about HIV/AIDS and its prevention, promotion of safer sex including the use of condoms, and adequate treatment of sexually transmitted diseases which significantly increase the risk of HIV transmission.

The health of mothers and children

Overall, breast-feeding provides substantial benefits to both children and mothers. It significantly improves child survival by protecting against diarrhoeal diseases, pneumonia and other potentially fatal infections, while it enhances quality of life through its nutritional and psychosocial benefits. In contrast, artificial feeding increases risks to child health and contributes to child mortality. Breast-feeding contributes to maternal health in various ways including prolonging the interval between births, and helping to protect against ovarian and breast cancers.

However, there is evidence that HIV – the virus that causes AIDS – can be transmitted through breast-feeding. Various studies conducted to date indicate that between one-quarter and one-third of infants born worldwide to women infected with HIV become infected with the virus themselves. While in most cases transmission occurs during late pregnancy and delivery, preliminary studies indicate that more than one-third of these infected infants are infected through breast-feeding. These studies suggest an average risk for HIV transmission through breast-feeding of 1 in 7 children born to, and breast-fed by, a woman living with HIV (i.e. infected with HIV).

Additional data are needed to identify precisely the timing of transmission through breast-feeding (in order to provide mothers living with HIV with better information about the risks and benefits of early weaning), to quantify the risk attributable to breast-feeding, and to determine the associated risk factors. Studies are also needed to assess other interventions for reducing mother-to-child transmission of HIV infection.

Elements for establishing a policy on HIV and infant feeding

1. Supporting breast-feeding

As a general principle, in all populations, irrespective of HIV infection rates, breast-feeding should continue to be protected, promoted and supported.

2. Improving access to HIV counselling and testing

Access to voluntary and confidential HIV counselling and testing should be facilitated for women and men of reproductive age, in part by ensuring a supportive environment that encourages individuals to be informed and counselled about their HIV status rather than one that discourages them out of fear of discrimination or stigmatization.

Prévenir l'infecti à VIH chez les f es

La grande majorité des enfants infectés par le VIH ont reçu le virus de leur mère, elle-même infectée le plus souvent par voie sexuelle lors de rapports non protégés. Aussi est-il prioritaire, aujourd'hui et dans le long terme, de développer des politiques et des programmes visant à réduire la vulnérabilité des femmes vis-à-vis de l'infection à VIH, notamment leur vulnérabilité sociale et économique en améliorant leur statut dans la société. Les mesures pratiques immédiatement nécessaires comprennent l'assurance d'un accès effectif à l'information sur le VIH/SIDA et sa prévention; la promotion de la sexualité à moindre risque, y compris l'utilisation des préservatifs; et le traitement adéquat des maladies sexuellement transmissibles qui favorisent la transmission du VIH.

La santé des mères et des enfants

Globalement, l'allaitement au sein est très bénéfique aux femmes et aux enfants. Il contribue largement à la survie de l'enfant en le protégeant contre les maladies diarrhéiques, les pneumonies et autres infections potentiellement létales, tout en améliorant leur qualité de vie par ses vertus nutritionnelles et psychosociales. A l'inverse, l'allaitement artificiel augmente les risques de morbidité et de mortalité infantiles. L'allaitement au sein contribue également à la santé maternelle de multiples façons, par exemple en prolongeant l'intervalle entre les naissances et en aidant à protéger contre les cancers de l'ovaire et du sein.

Toutefois, il est aujourd'hui clairement établi que le VIH – virus responsable du SIDA – peut se transmettre par l'allaitement au sein. Plusieurs études conduites à ce jour indiquent qu'entre un quart et un tiers des enfants nés de mère séropositive pour le VIH deviennent eux-mêmes infectés. Si dans la plupart des cas cette transmission intervient durant la grossesse et au moment de l'accouchement, des études préliminaires indiquent que plus d'un tiers de ces enfants infectés par voie verticale le sont du fait de l'allaitement au sein. Ces études suggèrent un risque moyen de transmission par l'allaitement au sein de 1 sur 7 pour les enfants nés de mère séropositive et allaités au sein par celle-ci.

Des données supplémentaires sont nécessaires pour identifier précisément le chronogramme de transmission du VIH par l'allaitement au sein (afin de pouvoir fournir aux mères l'information la plus juste sur les avantages et les risques du sevrage précoce), pour quantifier le risque attribuable à l'allaitement au sein, et pour déterminer les facteurs de risque associés. Des études sont également nécessaires pour évaluer l'efficacité d'autres interventions visant à réduire la transmission du VIH de la mère à l'enfant.

Eléments fondamentaux pour l'élaboration de politiques concernant l'infection à VIH et l'alimentation du jeune enfant

1. Promouvoir l'allaitement au sein

En tant que principe général, dans toutes les populations, quel que soit le taux d'infection par le VIH, il faut continuer de promouvoir l'allaitement au sein.

2. Améliorer l'accès au test VIH et au conseil

L'accès au test VIH et au conseil volontaires et confidentiels doit être facilité pour les femmes et les hommes en âge de procréer, notamment en permettant l'instauration d'un environnement favorable qui encourage les individus à rechercher l'information et le conseil concernant leur statut sérologique vis-à-vis du VIH, plutôt qu'un environnement qui les en décourage par peur de la discrimination et de la stigmatisation.

As part of the counselling process, women and men of reproductive age should be informed of the implications of their HIV status for the health and welfare of their children.

Counselling for women who are aware of their HIV status should include the best available information on the benefits of breast-feeding, on the risk of HIV transmission through breast-feeding, and on the risks and possible advantages associated with other methods of infant feeding.

3. Ensuring informed choice

Because both parents have a responsibility for the health and welfare of their children, and because the infant feeding method chosen has health and financial implications for the entire family, mothers and fathers should be encouraged to reach a decision together on this matter. However, it is mothers who are in the best position to decide whether to breast-feed, particularly when they alone may know their HIV status and wish to exercise their right to keep that information confidential. It is therefore important that women be empowered to make fully informed decisions about infant feeding, and that they be suitably supported in carrying them out. This should include efforts to promote a hygienic environment, essentially clean water and sanitation, that will minimize health risks when a breast-milk substitute is used.

When children born to women living with HIV can be ensured uninterrupted access to nutritionally adequate breast-milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breast-fed. However, when these conditions are not fulfilled, in particular in an environment where infectious diseases and malnutrition are the primary causes of death during infancy, artificial feeding substantially increases children's risk of illness and death.

4. Preventing commercial pressures for artificial feeding

Manufacturers and distributors of products which fall within the scope of the International Code of Marketing of Breast-milk Substitutes (1981) should be reminded of their responsibilities under the Code and continue to take the necessary action to ensure that their conduct at every level conforms to the principles and aim of the Code.

Dans le cadre du conseil, les femmes et les hommes en âge de procréer doivent être informés des implications, pour la santé et le bien-être de leurs enfants, de leur statut sérologique vis-à-vis du VIH.

Le conseil pour les femmes qui se savent séropositives pour le VIH doit inclure la communication des informations les plus actuelles sur les bienfaits de l'allaitement au sein, sur les risques de transmission du VIH par l'allaitement au sein, et sur les avantages potentiels et les risques associés aux autres modes d'alimentation du jeune enfant.

3. Permettre un choix éclairé

La mère et le père étant tous deux responsables de la santé et du bien-être de leur enfant, et compte tenu des implications sanitaires et financières pour la famille entière des choix en matière d'alimentation de l'enfant, il convient de les encourager à prendre ensemble des décisions à ce sujet. Toutefois, ce sont les mères qui sont les mieux placées pour décider d'allaiter leur enfant au sein, notamment parce qu'elles peuvent être les seules à connaître leur statut sérologique vis-à-vis du VIH et vouloir exercer leur droit à garder cette information confidentielle. Il est donc essentiel de permettre aux femmes de prendre des décisions pleinement éclairées en ce qui concerne l'alimentation de leur enfant, et de les soutenir dans leurs décisions. Il faut pour cela mettre en œuvre des moyens pour promouvoir un environnement sain, principalement au travers de l'accès à de l'eau non polluée et à des installations sanitaires appropriées, permettant de réduire les risques liés à l'utilisation éventuelle de substituts du lait maternel.

Si un enfant né de mère séropositive peut avoir accès, sans interruption, à des substituts du lait maternel ayant d'une part les qualités nutritionnelles requises et étant par ailleurs correctement préparés et administrés, il sera moins exposé aux risques de maladies et de décès s'il n'est pas allaité au sein. Toutefois, lorsque ces conditions ne sont pas remplies, en particulier là où les maladies infectieuses et la malnutrition sont les principales causes de mortalité chez les enfants, l'allaitement artificiel augmente de façon significative les risques de morbidité et de mortalité infantiles.

4. Eviter les pressions commerciales en faveur de l'allaitement artificiel

Les fabricants et distributeurs de produits qui relèvent du Code international relatif à la Commercialisation des Substituts du Lait maternel (1981) doivent être rappelés à leurs responsabilités dans ce domaine et continuer à prendre toutes les mesures nécessaires pour se conformer aux principes et objectifs du Code.