THE IMPLICATIONS OF 'AIDS NOTIFICATION' FOR HUMAN RIGHTS AND HIV/AIDS PREVENTION IN SOUTH AFRICA:

An analysis of the proposed amendment to the Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions

(SA Government Gazette, R 485, 23 April 1999 and R 484, 23rd April 1999)

Submission of the AIDS Law Project, Centre for Applied Legal Studies
University of the Witwatersrand, Private Bag 3, Wits, 2050, Johannesburg
125ma3he@solon.law.wits.ac.za

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This submission is also endorsed by the Women's Health Project, the National Coalition for Gay and Lesbian Equality, the HIV/AIDS Treatment Action Campaign, Lawyers for Human Rights AIDS and Human Rights Programme, the Gender Research Programme at the Centre for Applied Legal Studies (CALS)

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1. INTRODUCTION

On April 23rd 1999 the Minister of Health published draft Regulations to add Acquired Immune Deficiency (AIDS) and AIDS related deaths to the Schedule of Notifiable conditions. If these Regulations become law all health professionals[1] will be required to:

(a) complete a written report containing information about people diagnosed with AIDS This report will be anonymous, but will include details about, age sex, population group, date of diagnosis, medical condition at time of diagnosis etc.

(b) report every AIDS diagnosis to "immediate family members and the persons who are giving care to the person … and, in cases of acquired immune deficiency syndrome (AIDS) death, the person responsible for the preparation of the body of such person."

The actions that are proposed in (a) and (b) are presented as if they are a logical extension of each other. But in reality they are very different. In essence what is being proposed is:

- **'Anonymous Vertical Notification'** of details about people diagnosed with AIDS to the Health Department;[2]

and

- **'Named Horizontal Notification'** of an AIDS diagnosis to "family members", "care-givers" and, in cases of AIDS related death, "people responsible for preparation of the body".

These two types of 'Notification' serve different purposes. They also have different consequences for human rights. Unfortunately, however, in the public debate that has taken place around Notification (both before and after the publication of the draft Regulations) these purposes have been conflated. On the whole

[1] In Government Gazette 485 the people responsible for Notification are described as "medical practitioners, a practitioner registered as such under the Chiropractors, Homeopaths and Allied Health Service Professions Act, or any other person legally competent to diagnose a and treat a person with regard to notifiable medical conditions." In this submission the term 'health professionals' is used to refer to all these groups.

[2] The procedures for this are set out in Regulations relating to Communicable diseases and Notification of Notifiable Medical Conditions, Government Gazette, No R2438, 30 October 1987

they have mistakenly and emotionally been understood to mean 'partner notification', which, it is commonly believed, is a measure that is needed to prevent 'innocent people' from being infected with HIV.

In this vein, AIDS notification has been widely misinterpreted to be an action that will roll back patient's rights to confidentiality and privacy. Thus, in 1996 Dr Olive Shisana, the former Director General of the Department of Health, described confidentiality "as a superficial constraint on health workers" and asked "whether we should not be introducing a programme of partner notification". Shisana warned of "a clear conflict of interest between the maintenance of confidentiality for the infected person and the right to information of those they come into contact with." [3] The Inkatha Freedom Party (IFP) has also on several occasions used similar reasons to raise this issue in the National Assembly.[4] Soon after the publication of the draft regulations a spokesperson for the New National Party was quoted as saying that 'Notification' was necessary because the "Human rights of HIV positive people cannot weigh more than the rights of HIV negative people."[5]

This is a serious misunderstanding of the purpose of AIDS Notification. In fact, judging by the evidence we would argue that, until the publication of the draft Regulations, it had not been the government's intention to propose 'horizontal AIDS notification' in order to undermine a patient's rights to privacy and confidentiality in the health care setting. The NACOSA National AIDS Plan (which the government adopted as its policy in 1994) describes confidentiality as a "non-negotiable" and the former Minister of Health, Dr Nkosazana Zuma, on many occasions publicly defended the right to privacy.[6]

In January 1998 in an attempt to clarify these issues Dr Zuma informed the AIDS Consortium that the primary intention of AIDS Notification was to "obtain sufficient information to plan appropriately for the health service needs of persons diagnosed with AIDS" [7]. Apparently confirming this a January 1998 'draft

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[3] Statement by Dr O Shisana at SADC European Union Conference on HIV/AIDS in Southern Africa, Malawi, December 1996. The African National Congress (ANC) distanced itself from the statements made by Dr Shisana. 'ANC Slams AIDS Confidentiality Move', The Citizen, 11 December 1996.

[4] For example, in an article in the *Sunday Times* (1997) Rabinowitz wrote "HIV and AIDS should be notifiable, not at death demographically, but by name while patients are alive. This would facilitate monitoring of the illness, avoidance of further pregnancies and treatment to prevent the birth of infected infants."

[5] The Star, 26 April 1999

[6] NACOSA, A National AIDS Plan for South Africa, 1994 – 1995, p. 29.

[7] 21 January 1998. The letter states: "It is my responsibility to obtain sufficient information to plan appropriately for the health service needs of persons diagnosed with AIDS. No one system will answer all the questions about the HIV/AIDS epidemic. However, we can only gain from the information to be gathered which will include age, sex and geographic distribution, types of opportunistic infections, bed space requirements, etc.

document on AIDS Notification in South Africa' written by the Department of Health listed the specific aims of making AIDS Notifiable as being:

- To monitor the AIDS epidemic, its distribution in the population;
- To assess the burden of disease, including data on duration of hospital stay;
- To monitor trends in patterns of AIDS-defining illness; and identify risk factors;
- To allocate funds appropriately for intervention programmes on care.

Information uses that are cited are:

- Planning intervention, care needs and their resource implications;
- Planning the supply of preventative treatment and required medicines;
- To improve the general standard of diagnoses of HIV-related conditions;
- To improve attitudes to dealing with HIV+ persons on the part of health care staff and civic society;
- ***To assist in increase (sic) the proportion of partners who are notified;***
- To improve the management of latent syphilis in HIV+ persons. [8]

From the above there seems to be one over-riding reason for AIDS notification: to collect better data to assist a range of interventions which require careful planning. Although the Department of Health document states that Notification will 'increase the proportion of partners who are notified', how or by what means this will be achieved is not set out.

In order to analyse the draft Regulations and examine their implications for human rights we must clearly distinguish between the two types of proposed AIDS 'Notification'. In relation to 'anonymous vertical Notification' it is necessary to analyse the ***capacity*** of the Department of Health (DoH) to gather the required information ***legally, ethically and efficiently***. In relation to nominal 'horizontal family Notification' the analysis will concentrate on ***the implications of mandatory disclosure by health professionals for human rights, good public health practice and HIV prevention.***

"With regards the process a special data-gathering form is being developed which does not include the patient's personal details. Data will be reported on an aggregated basis to the national Department of Health for planning purposes.
"We intend to implement an efficient reporting system that safeguard's the patient's confidentiality. We will incorporate lessons learnt from other countries to protect the patient's right to privacy."

[8] Prepared by the Directorate Health Systems Research and Epidemiology for "Limited Circulation", 7/1/98.

2. VERTICAL AIDS NOTIFICATION: CAPACITY FOR IMPLEMENTATION AND CONCERNS ABOUT CONFIDENTIALITY

A recent report titled *the Role of Notification in the AIDS epidemic* states that the World Health Organisation (WHO) and the Centers for Disease Prevention and Control (CDC) typically identify three elements as being crucial parts of effective disease surveillance. These are:

(i) the ongoing, systematic collection of health data;

(ii) the evaluation and interpretation of this data for the purpose of shaping public health practice and outcomes, and

(iii) the prompt dissemination of the results to those responsible for disease prevention and control.[9]

In addition, the assurance of confidentiality on databases containing names and or information about reported individuals is described as being a major factor facilitating data collection.[10] In this respect, those industrialised countries that have introduced systems for vertical HIV or AIDS Notification have gone to extraordinary lengths to improve systems to protect the confidentiality of the information gathered. Thus, far from emasculating the need for confidentiality, HIV or AIDS Notification actually imposes a need for a strengthening of privacy protections.

We would suggest therefore that an analysis of the proposal for vertical AIDS Notification in South Africa must consider whether the health system has (a) the capacity to gather useful information on AIDS ***and*** (b) the ability to protect the privacy of this information.

(a) Capacity for efficient data collection

South Africa has a fragile public health system that has generally been unprepared for the management and control of HIV /AIDS either from a preventative or a curative perspective. AIDS is a complex disease whose determinants are in personal behaviour patterns that are heavily influenced by the socio-economic

[9] Beyer R, *Public Health and Surveillance in the HIV Epidemic: The Role of Notification*, unpublished research paper, June 1999

[10] Ibid. p.6 states: "The history of public health departments in preserving regimes of strict confidentiality on databases containing names of reported individuals contributed enormously to the ease with which AIDS reporting became possible in some nations."

conditions in which people live. HIV infection is moving at a terrifying pace through South African society. By January 1999 it was estimated that over 3.5 million people were infected with HIV.[11]

AIDS is already contributing to increased morbidity and mortality. In 1997 approximately 40% of adult in-patients at King Edward VII Hospital in Durban had HIV related conditions. In 1998 it was estimated that there would be 120 000 AIDS related deaths nationally. [12] The scale of the epidemic means, therefore, that vertical AIDS Notification will be required to capture and analyse a considerable and rapidly increasing amount of data.

Improved notification of transmissible, infectious and communicable diseases, and of vital events such as births and deaths, has been identified by the government as an important strategy for the protection and promotion of public health. However, in South Africa the public health information system was, until recently, geared towards only a minority of the population. After 1994 the Department of Health had to include 'new' areas and 'populations' in South Africa where public health was not previously monitored. This included the annual surveillance of HIV prevalence which, before 1994, was not undertaken in the so-called 'independent states' and 'homelands'. The short-term consequence has been that poor reporting of existing Notifiable illnesses has got worse. Much of the information garnered is unreliable and provides only a very rough tool for health planning and interventions.[13]

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[11] Summary Report: 1998 National HIV Sero-Prevalence Survey of Women Attending Public Ante-natal clinics in South Africa.

[12] *HIV/AIDS in South Africa: The Impact and Priorities*, Department of Health, 1998, p.10.

[13] For critiques of AIDS Notification from an Epidemiological perspective see: i) Dr M Colvin, 'Should AIDS be Made Notifiable?' *South African Medical Journal*, 89, 2, 1999; ii) Dr S A Karim, 'Making AIDS a Notifiable Disease: Is it an Appropriate Policy for South Africa?' *SAMJ*, 1999.

The Department of Health has recognised the inadequacies of its health information systems and is attempting to improve them. According to the *1998 SA Health Review:*

> "District Health Information Systems are in the process of gradual change from a system characterised by central and bureaucratic control to a system that supports planning, implementation and evaluation at the periphery. A number of bottom-up initiatives are reducing the data collected al local level to the *minimum felt to be locally useful*, with a concentration on *useable indicators*, *standardisation of data collecting tools*, and *common definitions*." (p. 113)

In this context it could be argued that making AIDS Notifiable **nationally** will suddenly impose huge new demands on a health information system that is currently being re-structured with an emphasis on district information systems and the more accurate collection of a smaller amount of data.

In the case of AIDS notification, the weakness of health information systems will be compounded by the fact that AIDS has many clinical manifestations. It is not a single easily identifiable illness but a syndrome of many opportunistic infections (some of which are already scheduled as Notifiable medical conditions). Some of these are illnesses that were already epidemic and that pre-existed HIV. They are linked to the poor socio-economic conditions in which the majority of people live.

Very few health professionals have received training on how to diagnose AIDS, or how to treat people with HIV/AIDS. Therefore, unless an AIDS diagnosis can be confirmed with an HIV test, vertical AIDS notification is likely to produce wildly inaccurate results.[14] At present, however, access to HIV testing is mainly limited to urban areas. Nationally only 56% of clinics offer HIV testing. This figure represents 33% of rural clinics and 77% of urban clinics. [15] As the table below shows, quite often access to an HIV test at public clinics is most limited in the Provinces where HIV prevalence is highest.:

Province	Estimated HIV prevalence, 1998	Percentage of clinics which offer HIV testing
Eastern Cape	15.9%	39%
Free State	22,8%	79%
Gauteng	22,5%	75%
KwaZulu Natal	32,5%	48%
Mpumalanga	30,0%	79%
Northern Cape	9,9%	100%
Northern Province	11,5%	20%
North West	21,3%	46%
Western Cape	5,2%	97%

Therefore in order to make the statistics generated by AIDS Notification accurate – rather than a reflection of the random presentation of people with AIDS to facilities where HIV testing is available -- the Department of Health would have to dramatically improve access to HIV testing at hospitals and clinics.

[14] This refers both to both the illnesses are in fact HIV related and, if they are HIV related, whether the illnesses are caused by a collapse of the immune system to such an extent as to allow an AIDS diagnosis. Thus, although the World Health Organisation, CDC and others have created clinical guidelines for an AIDS diagnosis which do not require an HIV test, the lack of training of most health professionals means that there is significant scope for misdiagnosis. In the absence of training an HIV test is the best means to ensure the diagnosis is correct.

[15] Health Systems Trust, *South African Health Review*, p.3

It is for these reasons that a broad spectrum of expert opinion, including the Medical Research Council (MRC) and the former AIDS Advisory Committee, has repeatedly advised against making AIDS vertically notifiable.[16] This is despite the consensus between epidemiologists and the Department of Health on the need for better surveillance of HIV/AIDS.

(b) Protection of Confidential Information

A major factor that contributes to the difficulty of controlling the transmission of HIV is the high degree of stigma and widespread unfair discrimination against people with HIV.[17] If vertical AIDS Notification is to be introduced there will need to be strict systems to protect patient confidentiality – systems that are not necessary when collecting data, for example, on maternal death or TB.

'Vertical AIDS notification' is being proposed on an anonymous basis. Theoretically, therefore, it should not pose a threat to the rights to privacy of people with HIV/AIDS. However, there is considerable fear and suspicion that the information that is collected may be unlawfully disclosed to third parties. Health professionals frequently come under pressure from employers, insurance brokers and even the community to disclose the names of people diagnosed or dying of AIDS. Lack of understanding of what is a lawful request (and what is not) leads to the frequent unethical and unlawful disclosure of this information.

Amongst health professionals there is already widespread misunderstanding and disregard of confidentiality. Resource constraints mean that very few health facilities have the physical means to protect private patient information. The National STD/HIV/AIDS Review that was conducted in 1997 discovered manifold breaches of confidentiality and found this to be one of the main reasons for people's fear of being tested for HIV.[18]

(c) Conclusion:

[16] See Minutes of the AIDS Advisory Committee of 14 October 1997 and 3 February 1998. On both occasions the Committee passed resolutions advising against AIDS Notification.
[17] See M Heywood, 'Human Rights Violations and HIV/AIDS: The Implications for Equitable Development in South Africa', 1998. Available at www.hri.ca/partners/alp/
[18] The South African STD/HIV/AIDS Review, 4-18 July 1997, Comprehensive Report. Findings concerning breaches of confidentiality are also reported on p. 12, p.16, p.20, p.21, p.22

In view of all the above we would argue that at present South Africa does not have the capacity to make AIDS vertically notifiable. Without training of health professionals on how to make an accurate AIDS diagnosis and/or drastically improved availability of a confirmatory HIV test there will be huge scope for inaccurate reporting. This will mean that whatever data is collected on AIDS cases will be open to question. More seriously, it is likely that even anonymous reporting will lead to breaches of confidentiality and add to the stigma and unfair discrimination that is being experienced by people with AIDS.

3. HORIZONTAL AIDS NOTIFICATION: IMPLICATIONS FOR PRIVACY AND OTHER HUMAN RIGHTS

(a)Privacy:

There is a strong legal basis to the right to privacy in South Africa. According to the Constitution "Everyone has a right to privacy."[19] In addition, ethical and common law rules require health professionals to respect confidentiality and allow their patient's to make their own decisions about the disclosure of private information. Finally, the International Covenant on Civil and Political Rights (ICCPR) states "no one shall be subjected to arbitrary or unlawful interference with his privacy."[20]

Involuntary AIDS notification is obviously a violation of privacy. The justification for this seems to be concern about the danger that people with HIV/ AIDS may pose to sexual partners and others who are not informed of their HIV status. For many, this is considered sufficient grounds to breach constitutional rights to privacy. In this case the rights and interests of the uninfected are felt to be more important than those of the infected.

However, the draft Regulations do not propose mandatory Notification to sexual partners.[21] Instead they propose to make it mandatory for a health professional to inform:

- 'immediate family members'
- 'care-givers' and
- 'people responsible for the preparation of the body.'

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[19] Constitution of the Republic of SA Act, 108, 1996: Chapter II, s14

[20] Article 17, UNAIDS Guide to the Human Rights Machinery, p.34. The ICCPR was ratified by South Africa on December 10th 1998.

[21] This is not to suggest that mandatory Notification to 'sexual partners' would be a justifiable invasion of privacy. Such a proposal would be unenforceable. This is another instance where public health, as well as the interests of the individual at risk, are better served by voluntary counselling than by coercion.

These three vague categories are not defined. They appear to be arbitrary. They could include numerous people -- most of whom are normally at no risk of HIV infection from the person diagnosed with AIDS. Further, the draft Regulations do not offer health professionals any Guidelines about who, or on what basis, people in these groups should be given private information. As a result the decision about who is informed will be an arbitrary one -- determined *subjectively* by the health professional.

The right to expect that confidentiality will be respected in a health setting is a corollary of the legal entitlement 'everyone' has to privacy.

The importance of confidentiality of information about a person's HIV status -- and their right to choose how and when to disclose this information to others -- was confirmed in the Appellate division in 1994. In the famous *McGeary* case the court stated that even though "AIDS is a dangerous condition… this does not detract from the right to privacy of the afflicted person, especially if that right is founded on the doctor-patient relationship." The Court also recognised that although HIV is 'dangerous' (because there is no cure) this needs to be distinguished from the fact that it is not contagious: **"**There are many pathogens that are more infectious than HIV…"

In summation the Court declared that "in the case of HIV and AIDS there are special circumstances justifying the protection of confidentiality:"

> **"**By the very nature of the disease, it is essential that persons who are at risk should seek medical advice or treatment. Disclosure of this condition has serious personal and social consequences for the patient." [22]

Therefore, in so far as they propose mandatory horizontal AIDS Notification the draft Regulations dictate a breach of privacy that is unlawful, unethical and unconstitutional.

(b) Confidentiality and Disclosure

[22] Jansen van Vuuren and another NNO v Kruger 1993 (4) SA 842 (A)

Justice Edwin Cameron has written that "The HIV/AIDS epidemic has brought with it profound re-examination of the practical implications of the principle of confidentiality and the tenets of medical ethics generally."[23] Generally this re-evaluation has led to a re-confirmation of the principle of confidentiality.[24] But it is combined with a recognition that confidentiality must be balanced with the responsibilities that fall on health professionals to encourage and assist a person with HIV or AIDS to inform his or her sexual partners. Confidentiality linked to voluntary partner notification is therefore the international standard.[25] This is why pre- and post-test counselling are considered so important to HIV/AIDS prevention (see Appendix).

In South Africa this balance is evident from the *Guidelines on the Management of Patients with HIV/AIDS* that were issued by the South African Medical and Dental Council (SAMDC) in 1994. In the *McGeary case* the Appellate Division declared that the SAMDC Guidelines (referred to in more detail below) were legally enforceable and actionable. These Guidelines state that the "results of HIV positive patients should be treated at the highest possible level of confidentiality." They endorse the principle of 'informed consent' for an HIV test, stating that this means the health care worker has an obligation "to ensure that the patient is directed to appropriate facilities that will oversee his further care and, if possible, counsel his family and or sexual partners." Whilst the Guidelines accept that "ethically the health care worker has a right to inform

[23] E Cameron, "Confidentiality" Outline of Presentation to Judges Workshop on HIV/AIDS, Mumbai, January 1999

[24] See L Gostin and Z Lazzarini, Human Rights and Public Health in the AIDS Pandemic, Oxford University Press, 1997.

[25] See: *The International Guidelines on HIV/AIDS and Human Rights*, United Nations, 1998. These Guidelines recommend that States "enact or strengthen laws that ensure privacy and confidentiality." They also recommend (p.13) that that: "Public health legislation should authorise, but not require, that health care professionals decide, on the basis of each individual case, whether to inform their patients' sexual partners of the HIV status of their patient. Such a decision should only be made in accordance with the following criteria:

- The HIV positive person in question has been thoroughly counselled;
- Counselling of the HIV positive person has failed to achieve appropriate behavioural changes;
- The HIV positive person has refused to notify, or consent to the Notification of his/her partner(s);
- A real risk of HIV transmission to the partners exists;
- The HIV positive person is given reasonable advance notice;
- The identity of the HIV positive person is concealed from the partner(s), if this is possible in practice;
- Follow-up is provided to ensure support to those involved, as necessary.

identifiable sexual partners of the HIV-positive status of a patient" they qualify this by saying that disclosure must be with the consent of the patient. [26]

The draft Regulations dismiss such an approach to HIV/AIDS Notification. Therefore, whilst the proposals for vertical AIDS Notification are broadly in keeping with an international consensus on the principles of disease surveillance, the proposals for Horizontal Notification would make South Africa a pariah amongst democratic nations. If carried out, they would compel health professionals to behave contrary to international medical ethics and place South Africa in opposition to key principles of international law.

(c)The rights and ethical duties of health professionals

A key intention of the National AIDS programme and more recently of the 'Partnership Against AIDS' has been to move responsibility for the epidemic beyond just the health sector and to encourage all sectors of society to participate in HIV/AIDS prevention. Unfortunately the proposal for Horizontal Notification does the exact opposite.

Health professionals are already burdened with impossible demands concerning care and treatment. They are faced with ethical dilemmas concerning treatment and care in the face of the resource constraints that face the health sector. The proposals add to this burden. If enacted they will require health professionals to act unethically by disclosing information – without counselling -- to third parties. This proposals is contrary to their Constitutional rights to freedom of conscience and the SAMDC Guidelines which allow health professionals to use their own discretion to decide when notification without consent is justified.[27] Those health care professionals who refuse to act on the Regulations will be criminalised.

[26] See Fine, Heywood, Strode (eds) *HIV/AIDS and the Law: A Resource Manual*, 1997 p. 52 for circumstances where non-consensual disclosure can be justified.
[27] The Termination of Pregnancy Act sets an important precedent for freedom of conscience for health professionals by recognising those who have a conscientious objection to TOP.

(d) Impact on people living with HIV/AIDS: Equality and Human Dignity

The draft Regulations do not require health professionals to counsel the recipients of information about an AIDS diagnosis. Adding to this injury is the wrong assumption that 'family members' or 'care-givers' will not abuse a person with AIDS. Many will.

High levels of rape and domestic violence against women would suggest that involuntary AIDS Notification to male partners or spouses will place many women in great danger of violence. Gender inequality, particularly in relation to sexual rights, also means that disclosure by a male to a female partner will not automatically permit the practice of safer sex.

In the health sector, lack of training to deal with HIV/AIDS has led to a situation where health professionals are sometimes the least caring of people living with AIDS. For example, a doctor at Chris Hani Baragwanath Hospital recently commented to a newspaper:

> "Many of the nurses at the [primary health care] clinics hear a person has AIDS and figure, 'They're going to die anyway, I won't waste medicine on them.' They give them two aspirins and send them home."[28]

Finally, not even the family can automatically assumed to be a safe space. In 1998 a survey of public attitudes to human rights carried out by the Community Agency for Social Enquiry (CASE) included several focus groups of people with HIV. One of the topics of discussion was disclosure. The report commented:

> "Most of the participants felt that it was important to notify their partners, as they would be directly affected. Caution was expressed about disclosing one's status to family members. Some felt that they would not be able to tell family members until the disease had become advanced. Others felt that certain family members should be told, but even then it was not always possible to gauge what the reaction would be. There was a keen awareness that prejudice and bigotry were rife and that disclosure must be among those people, family and professionals, who could be trusted to provide the necessary support. This often required gauging what the reaction would be. Sometimes it was not always positive, which in turn reinforced perceptions that disclosure might

[28] *Mail and Guardian*, July 16- 22, 1999. A large proportion of the cases taken up by the AIDS Law Project concern unethical or unlawful behaviour by health professionals: see monthly case reports of ALP para-legals and attorneys, 1998 and 1999.

have negative consequences. 'Someone at home revealed that she was a sufferer, so they kicked her out of the home.' (reported a PWA from Kwazulu-Natal)"[29]

The draft Regulations recognise the relationship that 'family members, care-givers and people responsible for burial' have with the person diagnosed with AIDS. This also creates a duty of confidentiality on their part. In the words of Judge Cameron, "Confidentiality … entails something given in trust. For confidentiality to arise, there must be a relationship between the subject to whom the knowledge pertains, and the bearer of the knowledge, of such a nature as to import a duty on the latter not to repeat it (or to repeat it only in specified circumstances or on specified conditions)." [30]

We must presume that family members and others would be told by health professionals that their knowledge of the AIDS diagnosis should be treated as confidential information. However, the draft Regulations place no sanction on those who breach this confidentiality. Unlike health professionals, family members are bound by no legal code in this respect.

This creates a danger that arbitrary horizontal Notification by the health professional will set off a domino effect of serial breaches of confidentiality. Because of the stigma and discrimination that exists around AIDS this could have disastrous consequences for the person with AIDS and impact negatively on a whole range of their fundamental rights. The extent of unfair discrimination against people with HIV is not something that is being imagined by 'AIDS activists'. The monthly reports of ALP staff (which are available for inspection) reflect the multiplicity of acts of unfair discrimination. For example, employment is routinely denied to people with HIV. But employers are likely to find additional arguments not to employ people with AIDS. [31] Recently, the AIDS Law Project had to intervene to challenge the actions of officials from the South African Police (SAPS) and the Department of Welfare who had removed two infant children from their mother to a place of safety because it had been reported that she had HIV/AIDS. AIDS Notification could also lead to stigma against other family members, for example the person's children at school. If the information was widely leaked to the community, the prevailing misunderstanding about AIDS will lead to untold small insults that impact on a person's dignity and sense of self-worth and, as we saw with the response of some members of the community in KwaMashu to Gugu Dlamini, in extreme cases it could lead to violence and loss of life.

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[29] CASE, unpublished report of Public Attitudes to Human Rights in South Africa, 1998
[30] E. Cameron, Outline of Presentation on Confidentiality, 1999.
[31] Breaches of confidentiality arising from AIDS notification are likely to lead to even more severe discrimination because of the perception that people with AIDS are at the end-stage of their illness. In the past the progression from HIV infection to AIDS could

4. IS HORIZONTAL 'AIDS NOTIFICATION' A JUSTIFIABLE LIMITATION OF FUNDAMENTAL RIGHTS?

There are some human rights that modern democracies consider inalienable. These include the rights to life, human dignity and equality. However, the principle that not all human rights are absolute has existed throughout the history of the modern human rights movement. In particular, it has been accepted by governments and human rights activists alike that public health emergencies and disease control may occasionally justify the limitation of rights – although such limitations should do the minimum to interfere with the dignity of the person/people affected. This recognition is entrenched in both local and international law.[32]

In some jurisdictions a distinction is made in health legislation between 'Communicable and 'Notifiable' medical conditions. Communicable illnesses are those – such as Ebola or Typhoid -- that are highly contagious (usually water or air borne) and which justify measures such as quarantine, isolation and restrictions on travel. Thus in South Africa, for example, the Regulations Relating to Communicable Disease and Notification of Notifiable Medical Conditions (Regulation no 2438, 30 October 1987) allow authorities to close schools, prohibit public gatherings, and isolate individuals to contain communicable illnesses.[33] This has not been challenged as unconstitutional.

Under South African law the right to privacy (and therefore also the obligation of confidentiality) may be limited. But when such limitations are being considered, the government is instructed to act in a manner

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not be reversed. However, modern treatments mean that a person with an AIDS diagnosis may, after treatment, have their immune system partially restored.

[32] Article 4 of the ICCPR states that "In time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, colour, sex, language, religion or social origin."

[33] Theoretically, such measures could be taken against people with AIDS, which is still listed in the schedule of Communicable diseases. However, the government has never acted on this provision, recognising, in the words of the European Parliament that that **"**it is impossible to accept discrimination based on a disease that is transmissible but not contagious." See: AIDS in the World I, AIDS and Human Rights, 548-549.

that is “reasonable and justifiable in an open and democratic society” and to “take into account all relevant factors, including:

“the nature of the right; [that is being limited]
“the importance of the purpose of the limitation;
“the nature and extent of the limitation;
“the relation between the limitation and its purpose; and
“less restrictive means to achieve the purpose.”[34]

The **nature** of the proposal for Horizontal AIDS notification is one that **wholly** and directly **disregards** the fundamental right to privacy. The **purpose** of the limitation seems to be to protect other people from HIV infection and to enhance care.

In view of the relationship between the limitation and the purpose, we would argue that horizontal AIDS notification does not pass this 'limitations test' because:

- A person diagnosed with AIDS will usually have been infected with HIV for many years. In all probability, Notification will come too late to protect family members (sexual partners) from the risk of HIV infection.

- ‘Family members’ and ‘care-givers’ face only a small risk of HIV infection and therefore the arbitrary disclosure countenanced by the draft Regulation cannot be justified;[35]

- Not all people who are told of an AIDS diagnosis will have access to latex gloves or other universal precautions needed to protect themselves from the possible risk of HIV infection;

- The limited access to health care services, particularly in the rural areas, will mean that the Department of Health will only have the capacity to diagnose and notify a small number of AIDS cases in South Africa (and even here with a high degree of inaccuracy). It will therefore impact unequally on a minority of people with AIDS.

[34] Constitution of the Republic of South Africa, Chapter 2, Bill of Rights, S 36(1)
[35] For a care-giver or a person responsible for preparing a body for burial to be infected with HIV, he or she would have an open cut or lesion that was directly exposed to the blood or bodily fluids of the person with AIDS. Scientifically this risk is extremely small. It could be more effectively reduced by much less restrictive means -- effective public education about the use of ‘universal precautions’.

Horizontal AIDS Notification will therefore not achieve the purpose that is given by the Department of Health. In fact it may do exactly the opposite:

- Public misunderstanding about the purpose of AIDS Notification (see the arguments made in section 1 of this submission) risks creating a false sense of security that will lead people to believe that, unless they are notified that a sexual partner/family member has AIDS, it is safe to continue dangerous practices, including unsafe sex and handling bodily fluids without using universal precautions.

- People informed of an AIDS diagnosis without counselling and support may choose to stigmatise and withdraw care from the person with AIDS.

- People who know (or think) that they have AIDS will avoid seeking care and treatment at health facilities because of their fear of discrimination arising from the legal requirement health professionals have to disclose their diagnosis.

- People who do not understand the difference between asymptomatic HIV infection and AIDS will be discouraged from voluntary HIV testing.

Ultimately, successful public health measures to reduce the number of new HIV infections will depend upon convincing the public *always* to act upon public health instructions concerning safer sex and to use universal precautions when handling blood or any bodily fluids. There are clearly less restrictive means than AIDS Notification to achieve this purpose.

On this basis, we would argue the horizontal Notification will not achieve the purpose for which it is intended. This would suggest that there can be no justification for the limitations it will impose on fundamental rights to human dignity and privacy.

4. RECOMMENDATIONS FOR LESS RESTRICTIVE PUBLIC HEALTH STRATEGIES:

The prevalence of HIV infection in South Africa has reached crisis proportions – and an extraordinary commitment of resources and will is needed if the epidemic is to be brought under control. The primary aims of the draft Regulations – to improve AIDS surveillance and prevent avoidable HIV infections -- are a recognition of this. However, we believe that there are less restrictive and more effective ways of doing this.

We urge the Minister of Health to withdraw the draft Regulations and instead to consider the following recommendations.

(a) HIV / AIDS surveillance

- Request the Medical Research Council (MRC) to convene a national consultation aimed at achieving consensus on a National HIV/AIDS Surveillance Protocol and the rapid implementation of surveillance projects that are both ethical and legal and which will provide accurate information about the prevalence, incidence and demographics of HIV/AIDS in South Africa.

- Provide training to health professionals to ensure that existing means for data collection, such as the confidential epidemiological information form that is attached to the Medical Certificate on Death, yield accurate and usable data.

(b) Confidentiality and Disclosure

The draft Regulations have created considerable misunderstanding about the government's commitment to privacy and confidentiality in the context of HIV/AIDS. This is fuelling stigma and assisting those who attempt to rationalise unfair discrimination. It has also created fear amongst many people living with HIV/AIDS.

We urge the Minister of Health and the Inter-Ministerial Committee on HIV/AIDS to:

- Make a public statement supporting the right to privacy and confidentiality of medical information.

- Launch a national campaign on 'Openness, Acceptance and Equality' which encourages disclosure and normalises HIV infection.

- Issue a call for increased voluntary testing and counselling for HIV infection.

- Call on organisations with an influence on public behaviours and attitudes (such as churches and trade union federations) to popularise sexual rights and responsibilities.

- Appeal to the private medical sector to provide significant resources to improve access to HIV testing in urban and rural areas and allow the rapid training of lay counsellors and health care professionals.

[Ends]

Appendix:

Some Additional Considerations on HIV Testing and Informed Consent

The draft Regulations do not refer to the current legal requirement for health professionals to obtain informed consent prior to HIV testing. But, given that they would probably lead to an increase in HIV testing, as well as pressure on health professionals to diagnose AIDS cases, the following legal requirements should be borne in mind.

(a) HIV testing

***What is proposed**:*

The draft Regulations do not propose to make HIV notifiable (only an AIDS diagnosis). To circumvent the problem posed by limited access to HIV testing the DoH does not intend to make a confirmatory HIV test a requirement for an AIDS diagnosis and therefore a pre-condition for reporting and family notification.[36]

Current legal position:

A health professional may have strong clinical indications that lead him/her to believe that a patient has AIDS. However we believe, an AIDS diagnosis should only be made with certainty on the basis of a positive HIV test.[37] The law is unclear on the legality of informing a patient of an AIDS diagnosis without the certainty of an HIV test. However, it would obviously be unethical for health professionals to inform a patient that they have AIDS without a confirmatory HIV test. To then report an unconfirmed and therefore uncertain AIDS diagnosis to others would be unlawful and could lead to civil suits against the health professional and/or the Department of Health on a number of grounds.

Implications for human rights:

Making it a legal requirement for health professionals to report an 'AIDS diagnosis' – without confirmation of an HIV test – creates the risk that patients will be informed that they have AIDS (for most people a fatal condition) without absolute certainty that it is not another treatable illness (such as TB). It will render people who may not have AIDS vulnerable to discrimination and stigma.

[36] This is evident from the draft Anonymous AIDS Notification form produced by the Department of Heath as well as from the stated intention to use the Bangui African AIDS case definition which "accommodates reporting where laboratory support is not available." Draft p.8.

[37] This does not in any way prevent a health care worker from treating what may be symptoms of AIDS or from advising the patient about safer-sex etc. as if they did have AIDS.

(b) **Counselling and Informed Consent:**

What is proposed:
The draft Regulations do not set out the legal and ethical responsibility that that falls on health professionals to ensure proper counselling takes place when a person is informed of an AIDS diagnosis. This is as necessary as the obligation on the health professional to ensure that a person being tested for HIV receives proper pre- and post test counselling and provides informed consent.

In addition, if the people who are informed of an AIDS diagnosis are to respond to this information in a manner that is rational and caring, and if they are to appreciate the need for confidentiality, they too will have to receive counselling from the health professional responsible for Notification.

Current legal position:
It is internationally agreed that pre- and post-test counselling must accompany HIV testing.[38] Common law in South Africa has recognised the principle that informed consent must be given by a patient before a medical operation.[39] This rule also applies to HIV testing.[40] A National Policy on HIV Testing and Informed Consent was recommended by the SA Law Commission in 1997 and was endorsed by Parliament.[41]

The South African Medical and Dental Council (SAMDC) Guidelines on the Management of Patients with HIV/AIDS state that "a patient should be tested for HIV infection only if he gives informed consent".[42] The SAMDC Guidelines, set out the minimum standards that constitute informed consent as including a verbal discussion (pre-test counselling) "so that the patient clearly understands what the purpose of the laboratory test is." They also state that the principle "entails that the health care worker accepts that if the patient were HIV positive, appropriate counselling will follow." These Guidelines were found to be legally binding on health professionals by the Appellate Division.[43]

These principles are also supported the NACOSA National AIDS Plan, which was adopted as the national AIDS strategy by the Department of Health in 1994.

Implications for human rights:
Unless there is extensive public education about the draft Regulation it is likely that it will be understood by many health professionals as a legal sanction to disregard the requirement for counselling.
Access to pre- and post-test counselling is minimal and almost non-existent outside of teaching hospitals and urban clinics. In 1997 the National HIV/AIDS and STD Review found that counselling services were not "uniformly available" and that "some clients reported the damaging experience of being tested without consent or counselling."
In 1998 the South African Health Review found that 70% of hospitals had policies for Informed Consent, Pre-test Counselling and Confidentiality, but noted that "these findings do not necessarily reflect that each of these policies comply with what is generally considered to be acceptable."

% of	District	Regional	Rural	Urban	Average

[38] World Health Organisation/ Global Programme on AIDS. *Statement from Consultation on Testing and Counselling for HIV Infection.* Geneva, November 1992.
[39] Stoffberg v Elliot 1923 CPD 148; Castell v De Greff 1994 4 SA 408 ©
[40] C v Minister of Correctional Services, 1996 (4) SA 292 (T)
[41] SALC, Project 85, First Interim Report on Aspects of the Law Relating to AIDS, February 1997 pp 27-35.
[42] SAMDC Guidelines: The Management of Patients with HIV infection or AIDS, 1993
[43] Jansen van Vuuren and Another NNO v Kruger, 1993 (4) SA 842 (A)

Hospitals with policies on HIV testing	72%	79%	63%	91%	73%

More pertinently Mr Lucky Mazibuko, an HIV positive columnist with the *Sowetan* Newspaper, recently wrote: "we do have good counselling services. But…. most of those first class facilities and services are still in white hands. The majority of our people do not enjoy good counselling services. We have eleven official languages. English is the medium of instruction. Consequently, other languages remain marginalised. Which is most unfortunate because most people feel comfortable being addressed in their own languages. Particularly when dealing with personal issues relating to a profoundly complex subject such as this thankless virus."[44]

There are, therefore, several conclusions that need to be drawn here. The first is that because counselling of all people who receive an AIDS diagnosis is a legal responsibility that exists for all health care workers, the DOH has a responsibility to ensure the availability of qualified counsellors. The second is that horizontal Notification would also require proper counselling of other people who are informed of the AIDS diagnosis – including counselling on the need for confidentiality to be respected.

[Ends]

[44] AF-AIDS PRE-ICASA 1: Discussion on HIV/AIDS Counselling in the African Context, 16 6 1999.