

Panel 3 Privacy, Confidentiality and Testing (3rd Person and Partner Notification) the legal perspective regarding privacy and confidentiality

Paper by Ratu Joni Madraiwiwi Private Legal Practitioner, 12th April 2007, Pacific Regional High Level Consultation on HIV and the Law, Ethics and Human Rights 11-13 April 2007, Auckland, New Zealand.

The right to privacy is a basic human right. It is enshrined in the UN Declaration of Human Rights and other International Instruments. Confidentiality as in the relationship between doctor and patient and the obligation to keep personal details private is an extension of that right. In the Pacific, only Fiji and the Marshall Islands have constitutional safeguards relating to privacy. Few States in the region have as yet legislated to ensure the privacy and confidentiality of those with HIV/AIDS. Only Papua New Guinea has enacted the HIV/AIDS Management and Prevention Act 2003 and Pohnpei, one of the constituent states of the Federated States of Micronesia, passed the Pohnpei Aids Prevention and Control Act of 2006. Some of the other Pacific Island States have policy guidelines in place while they seek to draft integrated HIV/AIDS legislation.

The right to privacy and confidentiality of people with HIV/AIDS continues to face practical and competing challenges. The dearth of constitutional and legislative provisions to reinforce and anchor this right emphasises the vulnerability of those affected. This is now being addressed and will even be considered in the process of these consultations. As to the public interest and the right to disclosure, this is a constant and valid consideration that is a very real concern in societies where one is defined not as an individual, but by the family or clan to which he or she belongs. The argument is that where the rights of the community conflict with that of the individual, the former prevails. However, it is a well-established principle that where rights appear to conflict, an attempt must first be made to harmonise them. In present circumstances, disclosure assumes immediate harm to the community and mala fides on the part of the individual with HIV/AIDS. If the prospect of a third party being put to risk is necessary to breach confidentiality as per the Tarosoff doctrine, why should this precondition not apply to privacy concerns as well?

The point I am labouring is that categorising the dilemma as simply one of individual rights to privacy and confidentiality, as against the collective or community interest, is valid but unhelpful. Because the right to disclosure is premised on the prospect of a hypothetical or potential risk not an actual one. There is a larger issue here. Just as complete disclosure and mandatory testing take no account of the stigma, prejudice and disadvantage that inevitably flow from those outcomes, so the recognition and enforcement of individual privacy and confidentiality engenders trust, confidence and cooperation from those with HIV/AIDS. These scenarios are well-documented from numerous studies and research undertaken elsewhere. The advantage of this analysis is that it makes a

concerted effort to allow these collective and individual rights to co-exist with each other. What is at first blush an apparent case of competing or conflicting rights is placed in a larger context. That in the absence of a cure for HIV/AIDS and any real prospect being years away, the pandemic will be overcome by strategies that encourage rather than coerce the modification of behaviour.

The Courts have long retained the inherent power to assure privacy and confidentiality by either holding hearings in private or suppressing names. Because this does not sit well with the concept of open and transparent justice, it is not a power used frequently. Nevertheless the ends of justice might require that this be resorted to. It is quite conceivable that Pacific courts may be called on to do so as has happened in other jurisdictions. A Court will weigh the competing public and private interest and decide accordingly. What has prompted this development is the hysteria, misinformation and prejudice that continues to be generated against people with HIV/AIDS which is further exaggerated by the media. Is there a distinction here between these circumstances and the earlier situation discussed? They may be distinguished on the basis that the matters here are already in the public domain, and the Court must find a legitimate ground on which to assure privacy and confidentiality.

Employment law presents a particular challenge because people with HIV/AIDS are readily victimised once their plight is made public. Their situation is compounded by the absence of legislative protection in most Pacific jurisdictions. This has proved to be a fertile field for Employment Tribunals and Courts elsewhere as people with HIV/AIDS have sought legal remedies. While it is possible to pursue proceedings under the Bill of Rights provisions of our Constitutions, it is a cumbersome process. An appropriate draft of an Employment Act should provide for employment security and additional benefits where the person with HIV/AIDS is no longer able to work. In addition, it must ensure confidentiality of an employee's medical, personal information and HIV status. It should also prohibit HIV screening for general employment purposes such as transfer, promotion and recruitment. Mandatory testing for specific employment groups should also be proscribed. Without those protections, they stand little chance of being accorded fair treatment.

Medical records and information are problematic areas as well. While doctor – patient privilege is widely recognised, the need for other medical personnel to handle medical records and information necessitates that this duty be extended. This requires legislative intervention in place of the protocols which presently apply in the absence of statute. To that end, HIV-related information and documentation concerning an individual must be safeguarded from unauthorised collection or disclosure wherever they are kept. The use of HIV/AIDS-related information must be informed and voluntary consent. Mention has already been made of the circumstances in which the veil of secrecy and confidentiality need to be lifted. Although Pacific jurisprudence in this field has yet to develop, Courts in other jurisdictions have been very active. The Supreme Court of Canada in

Cuerrier's Case has held that HIV positive people have a legal duty to disclose their status before they have sex that places the other person at significant risk i.e. significant risk of HIV infection. In Williams case decided in 2003, the Canadian Supreme Court suggested that people who think there is a risk they are HIV positive have a legal duty to tell others. With respect, this proposition extends the law beyond reasonable limits. The causal connection between the duty and merely being 'at risk' is too remote.

Children have the right to privacy under Article 18 of the Convention on the Rights of the Child. This is a very difficult concept for Pacific societies to understand let alone accept. But as all the States in the region have ratified the Convention, Governments now have a duty to ensure that societal attitudes conform to their international obligations. In most cases the child will defer to the parents' wishes and the need for confidentiality and privacy is superfluous. However, one must recognize that not all children come from happy homes or have trusting relationships with parents. Where children are old enough to understand and appreciate their HIV status, they are entitled to privacy and confidentiality. They are entitled to keep their test results, HIV status and other information confidential if they wish. In real life, given their vulnerability and relative immaturity, it is likely that they will let their parents know. But if they decide against it, then that decision must be respected by all concerned. Given public perceptions of parental rights, these safeguards need to be legislated to underscore the needs to respect the wishes (and rights) of the child.

The HIV/AIDS pandemic is unlike any other humankind has known. The numbers speak for themselves: 65 Million infected, 25 Million dead and counting. What role must the law play? The prevalence and incidence of HIV/AIDS strongly suggests that only an integrated community-based approach will be effective in countering the pandemic. In this, the law must have an enabling and facilitative role which places those with HIV/AIDS at the head of their priorities. What is critical is an understanding and appreciation that a co-operative, and compassionate empathy must infuse and inform all the resulting initiatives. Without it, the HIV/AIDS pandemic may well continue to plague generations as yet unborn.

