



HIV/AIDS Legal Centre Incorporated (NSW) ABN 39 045 530 926

Ref: 2016 Public Health Review

3 June 2016

Dr Jeremy McAnulty
Director, Health Protection NSW
NSW Health
LMB 961
North Sydney NSW 2059

Via email: publichealth@doh.health.nsw.gov.au

Dear Dr McAnulty,

Statutory Review of the *Public Health Act 2010* (NSW)

The HIV/AIDS Legal Centre (HALC) was established in 1992 and has since then been a Specialist Community Legal Centre (CLC) funded by the State and Federal Governments.

The work of HALC is an essential part of creating the ‘enabling environment’: an environment best allowing HIV positive people to live well and free from fear and risk of harm due to their HIV status, and for engendering freedoms and empowerment among the community, including for those at most risk of contracting HIV, to reduce the incidence of HIV infection. The ‘enabling environment’ approach is a critical part of the Federal and NSW State HIV strategies, which reflects best practice and a world leading response to the HIV epidemic since the 1980’s.

HALC endorses the submissions prepared by ACON Health Ltd with respect to this review of the *Public Health Act 2010* (the Act).

This document outlines our position and what we foresee as the negative consequences of the proposed amendments to s.56 of the Act; these submissions should be read in conjunction with the submissions provided by ACON as referred to above.

In summary, HALC’s position regarding the review are as follows:

1. The human rights based approach to the Government response to the HIV/AIDS crisis has been the most successful and is internationally recognized as the best practice model. The approach engenders the ‘enabling environment’ to allow, encourage and support self-care and treatment among those affected and affected communities.
2. NSW was historically a leader in public policy and Government action to address the problems HIV presents.
3. We welcome the proposed removal of s.79 from the Act and the proposal to include a statement of principles. We agree with the rationale behind this proposed change as articulated in the NSW Health Discussion Paper.

4. We further welcome the proposal that there be greater transparency requirements in the Act relating to public health orders that have been made. We caveat this by stating that, clearly, this transparency should be protected by appropriate privacy protections ensuring that the identity of any person that is subject to a public health order be protected.
5. S.56 of the Act in its current form creates an architecture of protections and obligations, somewhat balanced to engender both trust and the enabling environment.
6. Although circumstances have changed such that HIV is no longer a terminal illness, stigma and discrimination, fear and alienation continue to persist in at risk communities and for those with HIV.
7. The suggested changes to the s.56 of the Act substantially reduce the protections. They significantly impair the Department of Health's and the Government's ability to sustain the enabling environment.
8. Amendments to s.56 of the Act in the terms currently suggested will degrade the 'enabling environment' as well as the Government and NSW Health's ability to prevent and respond to HIV in a sophisticated way.

Background

Australia's response to HIV is internationally esteemed. That response has been driven by strong leadership from government working in partnership with health care providers, academic researchers, community based agencies and affected communities. The estimated prevalence of HIV in adults in Australia is around one sixth of that in the United States, and one third that in Canada and France.

The response has been further assisted by ensuring the existence of a supportive legal environment where the rights of HIV positive persons are respected and protected. Australia's successful response has been underpinned by the 'enabling environment': an environment where people living with HIV are encouraged and supported to participate in social, policy and legal decisions relating to HIV prevention – that is, support and information being a more effective means of preventing the spread of HIV than coercive and/or punitive legal interventions. The 2002 ANCAHRD paper, *Reforming the Law to Ensure Appropriate Responses to the Risk of Disease Transmission*, states that 'punishment under public health or criminal law should be reserved for the most serious cases of culpable behaviour as a last resort'¹.

NSW has long been a leader in adopting this human rights approach to HIV by creating a supportive social and legal environment where rights are respected and protected, and the equitable right to health is achieved. NSW has encouraged testing with privacy protections, facilitated access to treatment and care, and reduced the impact of stigma and discrimination; all essential to the public health management of HIV.

¹ ANCAHRD (2002), *reforming the Law to Ensure Appropriate Responses to the Risk of Disease Transmission* at p2.

Ensuring this continues means eliminating legal barriers to prevention programs by encouraging people who engage in high risk behaviours to engage with services and safely discover and/or address their health status early, without fearing breaches of human rights and privacy, discrimination and stigmatization, or reprisal. The current approach recognises that a minority of mainstream health care workers and yet more among the general community still discriminate against people based on HIV status. Effective health and public policy is directed to lessening the existence and impacts of HIV stigma and discrimination².

*HIV Futures 6*³ notes that more than 25% of those surveyed have experienced discrimination in a health care setting.

The stated objectives of the Act are:

- (a) to promote, protect and improve public health,
- (b) to control the risks to public health,
- (c) to promote the control of infectious diseases,
- (d) to prevent the spread of infectious diseases,
- (e) to recognise the role of local government in protecting public health.

HALC submits that the proposed amendments to s.56 of the Act fail to embody those objectives and undermine existing best practice in relation to public health objectives.

Section 56

Our experience is that despite concerted efforts in Australia to reduce the stigma surrounding HIV, people living with HIV remain highly marginalised. This is particularly true in key affected and vulnerable groups including: people from culturally and linguistically diverse (CALD) backgrounds, women, Aboriginal and Torres Strait Islanders, sex workers, injecting drug users and people in rural and regional Australia. Despite the recognition of HIV as a chronic medical condition, we deal with clients who face discrimination in multiple aspects of their lives based on their HIV status on a daily basis.

We contend that moving to a system of named notifications would be a significant shift in the current protections for people diagnosed with HIV. We note that s56 of the Act has two purposes. Section 56(1) deals with named notifications and s.56(3) requires service providers to take all reasonable steps to prevent disclosure of the fact that a person has HIV.

HALC's position is that named notification is undesirable. The reasons for this include:

- i) Named notification would increase barriers to testing, as medical practitioners would have to disclose to patients that information gathered during pre and post-counselling (such as mode of exposure) would be passed to NSW Health in association with the patient's name;
- ii) Named notification links not only a person's HIV diagnosis to their name, but also other personal information such as cultural background, sexual history/habits and history of injecting drug use for example and thus creates a large and identifiable

² Paraphrased from National HIV Strategy 2010 [DRAFT]

³ Grierson J, Power J, Croy S, Clement T, Thorpe R, McDonald K, Pitts M. *HIV Futures 6: Making Positive Lives Count. The Living with HIV Program*. Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University; 2006.

- quantity of sensitive data about people with HIV that could be subpoenaed under civil or criminal proceedings;
- iii) Named notification could undermine the overall quality of the data collected by NSW Health, if patients become less inclined to honestly answer questions asked by their doctor on the notification form;
 - iv) We note that, rightly, the proposed changes are not retrospective and therefore it will not be possible in any event to achieve accurate data collection;
 - v) We note that, rightly, the proposed changes continue to allow for confidential testing and therefore it will not be possible in any event to achieve accurate data collection;
 - vi) Named notification has the potential to negatively impact rates of testing due to the removal of coded notification, as well as to create a disincentive to continuity of care; and
 - vii) Named notification could expose NSW Health to legal action for breach of duty of care as it will be easier for NSW Health to clearly identify people who *may* be placing others at risk.

An intrusive, proactive approach goes directly against the nuanced and sophisticated approach that NSW Health has so far used successfully in engendering behavioural change among the small minority of people with HIV who place others at risk and jeopardises the significant and world leading approach of NSW Health to date.

If changes are made to s.56(1), it will be important to ensure that the confidentiality provision in s.56(3) is maintained. We also contend that if changes are made to s.56(1) then it would be necessary to ensure that there are legislative protections prohibiting the disclosure under subpoena or FOI; and that these protections be far reaching and ensure that all courts, tribunals and government (both federal and state) agencies be captured. We note some legislation prohibits access even by subpoena, however this often comes with caveats, for example Family and Community Services records relating to child protection are still accessible in Family Court proceedings.

The proposed changes to s.56(3) of the Act may open clients up to further stigma and discrimination and make people living with HIV feel less in control over their health and medical records. We note that stigma and discrimination towards people living with HIV is reported to occur in a health care setting more often than in any other setting.

Although we oppose the removal of s.56(3), we contend that if s.56(3) is removed, which we acknowledge may in some instances be beneficial for the treatment of the patients, that medical practitioners should clearly inform their patients that their personal health information will be made available to other health care providers who are involved in the provision of their medical care or treatment and where the information is relevant to the provision of that care. Knowledge of this fact will ensure that clients are not 'blindsided' by other health care providers being aware of their HIV status to hopefully ameliorate the feeling of lack of empowerment and control over their personal information.

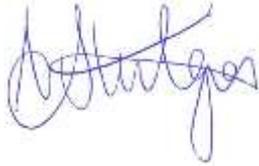
Recommendations

1. That the current provisions of s.56 of the Act remain unchanged;
2. That s.79 of the Act be removed and a statement of principles, which encourages everyone to take responsibility for their own and their sexual partners' sexual health be inserted; and

3. That there be greater transparency around public health orders that have been made.

We thank you for your careful consideration of our submission and the time given to hearing from the community in relation to the proposed changes. Please contact us if you require any further information.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Alexandra Stratigos', written in a cursive style.

Alexandra Stratigos
Co-Principal Solicitor