

Submission

No 27

INQUIRY INTO THE OPERATION OF THE HEALTH CARE COMPLAINTS ACT 1993

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Parliamentary Joint Standing Committee on the Health Care Complaints Act
Inquiry

**SUBMISSION OF
POSITIVE LIFE NSW
AND
HIV/AIDS LEGAL CENTRE INC.**

We thank the Joint Standing Committee for the opportunity to make this submission in relation to its enquiry into the Health Care Complaints Act 1993.

This is a joint submission by Positive Life NSW Inc. (*Positive Life*) and the HIV/AIDS Legal Centre Inc (*HALC*).

This submission is structured as follows:

1. Community standing and experience of Positive Life NSW and HALC;
2. Issues of concern for Positive Life NSW and HALC: we identify a range of concerns in relation to the current model and practice of the HCCC which are illustrated via case studies;
3. Potential governance role for the HCCC and the benefits to our clients;
4. Conclusion and Recommendations.

1. Community standing/experience: Positive Life NSW and HALC

Positive Life NSW is a non-profit community organisation representing the interests of people living with HIV across New South Wales. Since 1988, we have provided health promotion and education, advocacy, and peer support. Our representation on various government and non-government bodies aims to ensure that people with HIV are able to access quality health care and participate within the community in ways that enhance the quality of life, for them, their partners and their families. Positive Life NSW has extensive knowledge and experience of the contextual issues impacting on the health and welfare of people living with HIV in NSW.

Established in 1992, HALC provides legal advice and representation to people with HIV and Hepatitis C (HepC) related legal matters. HALC has extensive experience and knowledge of a broad spectrum of issues and concerns of the HIV and HepC

¹community, and a strong awareness of the many services that are offered and how best they can provide for the needs of clients.

HIV continues to be met with uncertainty and fear by members of the community, including those in healthcare settings. As the Joint Standing Committee will appreciate, HIV is a chronic illness and requires a wide range of healthcare support, some of which is ongoing and complex. HIV continues to be associated with sexual activity, infectivity and drug use. As a result, disclosure of HIV status potentially exposes people to stigmatization and discrimination. It should be noted that HIV disproportionately affects those communities in the population that already face discrimination in society.

Positive Life NSW and the HIV Legal Centre (HALC) have considerable experience in relation to health care complaints by people with HIV in NSW. Numerous points of intersection between people with HIV and health care services, provides Positive Life and HALC with an understanding of the relationship between the HCCC and client complaints against health care professionals and providers.

Because people with HIV still experience stigma, their relationship with health care providers often assumes greater importance in their lives. As the StraightPoz Study, reports: *'the most frequently mentioned instances of discriminatory treatment were in relation to interactions with healthcare professionals. The most common forms of discrimination were breaches of confidentiality, being treated with suspicion or curiosity by doctors and hospital staff, and having assumptions made about how they became infected[...].'*²

Further, Futures Five reports; *The introduction of anti-discrimination legislation has offered an avenue of redress for those with the energy and courage to pursue it[...]. However people with HIV continue to experience less favourable treatment in many domains of their lives. While more research needs to adequately assess the specific impact of this treatment, we can reasonably imagine that the impact goes beyond the direct outcomes of these actions and is detrimental to both health and quality of life. In addition, the anticipation of discrimination may limit people's life choices in subtle but substantial ways.*

27.2% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This compared with 10.1% of all respondents that had experienced such discrimination in the last two years and 17.1% that had experienced this more than 2 years ago. When asked what form this discrimination took, the most

¹ In this document for convenience, and because in our experience the issues concerning both communities are concordant in respect of these submissions, we shall refer only to HIV and people living with HIV and not to HepC and Hepatitis C positive people.

²Asha Persson, StraightPoz Study, Volume 1, Monograph 2/2006 National Centre for HIV Social Research, UNSW 2006, p 15.

common responses were increased infection control (35.6%), avoidance (34.5%), confidentiality problems (31.6%), treated last (29%), refusal of treatment (29%), rushed through (27.7%), harassment (9.3%) and abuse (8.4%).’³

These factors highlight the importance of the HIV community having a fair and effective complaints body that ensures health care professionals provide standards of treatment and care that are expected of them by the industry regulatory authorities, health care policy and the community.

2. Issues of Concern for Positive Life and HALC in relation to HCCC

2.1 The lack of awareness by HCCC staff of legal and medical HIV related issues, particularly in regard to HIV stigma, discrimination, confidentiality and HIV (pre and post test) counseling.

This general concern emerges from our casework experience with clients both complaining to the HCCC, and subject to prosecution by the HCCC. The case studies (refer to appendix 1) provide evidence of the specific instances where lack of awareness of HIV has impacted on effective outcomes.

We submit that in one case, the HCCC’s failure to appropriately refer a matter to the Impaired Nurse Panel rather than prosecuting the nurse highlighted the lack of knowledge by HCCC staff about policies governing HIV positive healthcare workers, and a lack of understanding of the issues. This significantly disadvantaged the HIV positive health care worker, and resulted in a long and expensive process to produce a comparable result which the Impaired Nurse Panel would have generated. The HCCC dealings on this matter exhibited elements of arguably inappropriate discrimination and prejudice against people with HIV.

In another case, the HCCC did not understand the importance and scope of duties by doctors under the Public Health Act 1991 (NSW) and NSW Health Policies (*for instance*: PD2005_048) in relation to HIV pre and post-test counseling. Coupled with the cumbersome process undertaken by the HCCC, this lack of detailed understanding and knowledge of the law and policy resulted in no effective outcome or investigation of the issues by HCCC. The process spanned a period of two years.

2.2 The prolonged process and time period elapsing before progress (if any) is observed on a complaint.

³ J Grierson, R Thorpe and M Pitts (2006) HIV Futures Five: Life as we know it, monograph series number 60, The Australian Research Centre in Sex, Health and Society, La Trobe University, October 2006, pp 68.

Complaints to the HCCC are unnecessarily prolonged. As indicated above, one complaint continued for two years with no eventual outcome, nor any formal closure. The HCCC were entirely unsuccessful at obtaining a response from a government health service in relation to its compliance with mandatory NSW Health policy and NSW laws.

Many complainants will simply not have the energy or stamina to continue with the process.

Additionally, individuals who seek to utilize the HCCC as a preliminary forum for resolving a discrimination dispute could be severely jeopardizing their ability to pursue other legal options, if an amicable settlement is not reached at the HCCC.

Complaints made under the *Anti Discrimination Act (NSW)*, *Sex Discrimination Act (Commonwealth)* and *Race Discrimination Act (Commonwealth)* are subject to a limitation period of one year. This limitation period requires that individuals lodge their discrimination complaint at the Anti Discrimination Board (ADB) or the Australian Human Rights Commission (AHRC) within one year after the discriminatory incident occurred.

In instances where an individual has undertaken the HCCC process as a preliminary forum for resolving a discrimination complaint, before pursuing other legal options, the complainant can become effectively barred from making a formal complaint to the ADB or the AHRC and subsequent judicial review. This is because the HCCC complaint and resolution process often exceeds the one year period.

2.3 The inadequacy of the HCCC to provide tangible outcomes to complainants.

The HCCC does not provide a tangible outcome for the complainant. There is no provision for compensation for complainants. Only a prosecution by the HCCC following a complaint can force a defendant party to change its practice, and address the issues seriously.

The HCCC therefore has limited coercive power to bring parties to conciliate or otherwise resolve complaints in a constructive way. Likewise, there is no real impetus for systemic changes to issue from complaints unless there is a prosecution.

This coupled with the prolonged process employed by the HCCC makes any complaint an unattractive option for all but the most stoic of complainants and most severe complaints.

We submit the current model is not responsive to the full range of complaints and circumstances presented by complainants in NSW and the health care industry.

We demonstrate this by drawing attention to the following issues:

2.3.1 Conciliation

The process is managed by HCCC and no legal representatives are allowed. This creates a disparity between the complainant and professional practitioners.

Our experience has been that the HCCC has not used its conciliation functions as effectively as bodies, such as the Anti-Discrimination Board or the Australian Human Rights Commission. Clients have not been offered the option to access our knowledge and legal expertise. The HCCC requirement that legal representatives are not involved in conciliation leaves the complainant disadvantaged.

The HCCC having no compensatory or order making powers, nor there being recourse to a Tribunal with such powers means any conciliation process is weak. There is therefore no incentive to resolve matters.

2.3.2 Assisted Resolution

As the HCCC can not award compensation or damages; the only likely positive outcome is an apology. This is a laborious process for an apology which is rarely forthcoming. The HCCC seems to have been unable to progress a open disclosure (transparent) approach to complaints and medical error in NSW.

The HCCC objectives have been narrowly interpreted to target severe cases where patient's lives might be directly jeopardized, or where practitioners have breached registration or practice requirements (usually involving malpractice, drug use, theft or fraud). Discrimination and a patient's rights to dignity and confidentiality, attracts no interest from the HCCC in our experience.

2.3.3 No recourse to judicial review of HCCC decisions

Because there is no recourse for review (merits or judicial), this makes a complaint to the HCCC a dead end. We submit that these factors have contributed to the HCCC being unresponsive and unhelpful.

Our analysis of the data documented in the HCCC Annual Reports⁴ supports our experience.

⁴ HCCC Annual Reports 2007/2008 (Accessed via:
<http://www.hccc.nsw.gov.au/downloads/AR0607part1.pdf> and
<http://www.hccc.nsw.gov.au/downloads/AR0607part2.pdf>)

We note: The proportion of privacy/discrimination issues received by the HCCC in 2006/07 is 2.1% of all complaints, and is considered a positive outcome by HCCC - as highlighted in the report: *‘On a “positive” note, the proportion of complaints in the category privacy/discrimination dropped from 4.3% in 2005-06 to 1.7% in the reporting period. Within this category, fall issues such as breach of confidentiality and access to medical records.’*

It is also notable that the proportion of privacy and discrimination complaints discontinued, amount to a higher proportion of complaints made. Discontinued privacy and discrimination complaints amount to 3% of all complaints discontinued, while making only 2.1% of all complaints made.

Analysis of declining complaints

In Table 18.1⁵, we note that there has been a gradual decline in privacy and discrimination complaints as a proportion of total complaints made to the HCCC. We suggest that this means that fewer people view the HCCC as an effective body to deal with these complaints.

Table 18.1 Summary of privacy/discrimination complaints by issue category 2004-05 to 2006-07

2004/05	2005/06	2006/07
No.	No.	No.
110 3.6%	115 3.4%	68 2.1%

(We note that in the HCCC Annual Report 07/08, the proportion of privacy/discrimination complaints received has increased to 3%).

Over half of all privacy/discrimination complaints made in 2006/07 involved privacy/confidentiality issues. This indicates that there is a need for HCCC to become familiar with these concerns and have adequate measures for dealing with complaints.

The statistics contained in the HCCC reports suggest there is reluctance for claimants to utilise the HCCC in resolving disputes that involve breaches of privacy and incidents of discrimination. We submit this is due to the inadequacy of the HCCC to sufficiently resolve these types of matters and the considerable time involved in the HCCC complaint process. We suggest that a decline in the number of complaints does not equate to improved outcomes or service.

⁵ HCCC Annual Report 2006/7, p125

Positive Life and HALC assert that existing avenues under the *Privacy Act* and the *Anti-Discrimination Act* are currently better potential forums for handling these types of complaints. We do not believe that these avenues are ideal, particularly in relation to health care settings. We note minimal success in the use of these other complaints bodies by people with HIV. At a Positive Life NSW Forum on discrimination in employment held in 2008, a representative of the ADB was unable to identify any HIV related complaints to the NSW ADB in the last 15 years.

2.4. The inadequacy of HCCC in fulfilling a broader mandate in providing feedback, correction and improvement to health care provision in NSW (i.e. a role as a governance mechanism)

The objectives for the HCCC as set out in the *Health Care Complaints Act 1993 (the Act)* Sections 3 and 3A, define the role currently practiced by the Commission. This role is confined to a narrow reading of these objectives with an emphasis only on ‘prosecution in the most severe cases’.

As evidenced in the case studies (refer to Appendix1), the HCCC has been unable to translate complaints into changes in practice⁶. In our experience, the HCCC has singularly failed to understand the law and policy in relation to HIV and medical care. Even where it has understood the issues, it has failed to effectively translate the complaint into practical changes in healthcare practice on either a small or large scale.

The case study involving the nurse (refer to Appendix 1, case study1) who was prosecuted by the HCCC, demonstrates a lack of understanding of HIV, relevant policy and law. The HCCC failed to identify the better policy alternative of referral to the Impaired Nurse Panel. The HCCC ignored or misunderstood the relevant mandatory NSW health policy on the subject.

Case study 2, (refer to Appendix1.) involving the Health Services Australia doctor’s noncompliance with HIV pre and post test counselling protocols, indicated a lack of understanding of the law, and will to effect change in practice on a matter of public health importance.

2.5 The need for a judicial forum if complainants are not resolved by the HCCC.

⁶ Except presumably via successful prosecutions.

The current Health Care Complaints Act makes no provision for further review or recourse if matters are not resolved. This makes the HCCC a virtually pointless exercise for most complainants.

We no longer advise clients with healthcare complaints to file matters with the HCCC. Our experience is that clients can expect a lengthy process, resulting in no compensatory or order making powers, and little hope of a satisfactory or respectful outcome (except in severe cases).

2.6 A current perception that the HCCC is designed to defuse complaints rather than resolve them and provide remedies.

Presently HALC is reluctant to refer clients to the HCCC for privacy, confidentiality and discrimination related issues.

HALC has found that the HCCC operates ineffectively and there are therefore other more effective processes (for example the Anti-Discrimination Board, Administrative Decisions Tribunal and traditional civil proceedings). The HCCC is currently not recommended because it is often slower and more limited. In our experience, the HCCC is entirely ineffective in properly and thoroughly investigating complaints against medical practitioners and health care providers. The HCCC deflates complaints through fatigue and attrition.

Positive Life NSW and HALC recognises a need for an effective body for privacy/confidentiality and discrimination related issues that arise in the health care related context.

3. Potential governance role for HCCC

We submit that a more generous reading of Section 3 (2) would allow the HCCC to expand its role to better fulfill a 'governance' role. Better still; the Act might be amended to make provision for the HCCC to undertake such a role.

By a governance role, we mean a role where the HCCC engages with health care providers, the Department of Health, public health organizations and registration authorities in both formal and informal ways; in order to improve health care quality, policy and practices generally in NSW.

We propose that the HCCC would in best practice, draw on its direct and detailed knowledge of complaints, to generate policy and practice change at a systemic level.

Currently the only way the HCCC is empowered to participate in governance, is via prosecution of complaints. We suggest there is scope for a more sophisticated role for the HCCC.

An expanded governance role would allow HCCC to more flexibly utilise the range of information arising from complaints, to effect practical change and reform throughout the healthcare industry.

Best practice in Human Rights investigation and conciliation, exemplified in the Australian Human Rights Commission (Federally), and the Anti-Discrimination Board NSW, would provide a potential model for reforming the HCCC. These bodies currently provide effective complaint resolution processes, judicial review and identify issues for systemic practice, policy and legislative change.

In the emerging area of electronic health records for both patients and providers, the HCCC should be in a position to monitor, audit and identify systemic breaches by service providers. This area holds significant concern for people with HIV and Positive Life NSW both now in the establishment phase and into the future in operation and monitoring.

4. Conclusion and recommendations

We submit there are significant shortcomings in the current scope and practice of the HCCC. The HCCC is currently not responsive to non-prosecutable complaints, provides no effective outcomes for complainants, and is increasingly abandoned by many people not satisfied by the quality of health care provision.

This points to a significant vacuum in the translation of health care complaints into systemic improvements and evidence based practice, policy and legislative change.

The problems identified, point to an opportunity for effective changes in HCCC policy and practice. Systemic change and an effective feedback mechanism (that consistently and incrementally improves the standard of services and healthcare provision generally) will provide great benefit to complainants and the health care system. These models exist and have been well tested in the Human Rights sphere.

Recommendations

- 1) HCCC educate staff on HIV related issues, and the HCCC engage more actively and effectively in drawing on medical and legal expertise in the field when investigating complaints involving HIV related or other specialist areas of practice.
- 2) HCCC undergo reform and its processes, functions and outcomes are modeled upon best practice exemplars from Human Rights bodies such as the Australian Human Rights Commission (Federal) and the Anti-Discrimination Board (NSW).
- 3) HCCC Act be amended to reform its complaint handling process and outcomes in line with the Human Rights exemplars noted above.
- 4) People with HIV be able to make complaints in a de-identified manner prior to dealings with dispute resolution practitioners.
- 5) HCCC be empowered to recommend award compensation and damages at dispute resolution stages; and /or reinstatement of treatment.
- 6) HCCC governance role be enhanced by amending the Act and requiring the HCCC to report to parliament and relevant bodies (such as professional standards bodies and NSW Health) on issues arising from complaints.
- 7) HCCC be empowered to recommend policy, practice, training and legislative change where appropriate.
- 8) HCCC performance be measured by its effectiveness in bringing improvements in health care management, policy, governance and patient care: such measures would be incorporated as part of its annual reporting mechanisms (e.g. State Parliament).
- 9) *Health Care Complaints Act 1993* be amended to include a power of referral, to allow complaints to go before the Administrative Decisions Tribunal, similar to that contained in the *Anti-Discrimination Act*. That this power be used when the HCCC is unable to resolve the dispute.
- 10) Provision be made for an ongoing external review of the HCCC.
- 11) HCCC be empowered to monitor, audit and identify complaints and errors relating to the electronic health record (patient and service provider records) management and use in NSW, by all relevant service providers
- 12) HCCC to be enabled to identify and progress work to address systemic breaches and failures with the electronic health records management and reporting systems.
- 13) HCCC expedite all complaints, where discrimination is alleged, and advise complainants immediately on lodgment of a complaint, about the Anti-Discrimination Board and Australian Human Rights Commission.

We wish the Committee well in their inquiry into the operation of the Health Care Complaints Act 1993, and advise that we would be pleased to attend hearings of the Joint Standing Committee and give evidence, should we be invited to do so.

Yours sincerely,

Positive Life NSW
HIV/AIDS Legal Centre Inc.

Appendix

Case Studies:

Three case studies are based on common dealings between HALC and the HCCC.

Case Study 1 – This case involved a nurse who has HIV since 1988. He did not have symptoms until 2003. In 2004 he was admitted to hospital. Due to his illness our client was forced to discontinue employment. He had been employed at a rural hospital. He informed his employer of his HIV status and the complications.

Following recovery, our client was required to provide a return to work medical certificate. His GP was very confronted with our client's HIV status and expressed concerns regarding him practicing as a nurse. These concerns are contrary to accepted medical practice. There is no reasonable reason why a person with HIV is unable to practice as a nurse.

The Hospital (employer) and the treating doctor did not refer the nurse to the Impaired Nurse Panel. Neither did the HCCC when it had the matter, and when it would have been appropriate to do so.

His GP refused to draft the return to work medical certificate and instead provided a modified version that required our client to work with supervision and in a non-clinical capacity, preferably in a part time or casual capacity. Our client was not reemployed by the hospital and was informed that they were unable to provide suitable supervision for his employment.

Proceedings were then brought against him by the HCCC to the Nurses and Midwives Board of NSW (NMB) to have him deregistered due to the opinion that he was unable to perform the necessary duties.

The NMB determined that the nurse was required to undergo a series of psychometric tests to prove that he had the sufficient mental capacity to perform his role as a nurse. He had not received any complaint about his conduct or the performance of his nursing duties.

The NMB found that despite the nurse's HIV related dementia having limited impact on his role, the NMB imposed serious conditions on his ability to work as a nurse, including conditions relating to the Nurse's maintenance of his own treatment. The orders included that he provide medical reports from his GP and psychologist to the NMB; that he undergo annual psychometric testing for the NMB; and that he fully disclose his medical condition to any new employer.

No patient had been harmed by the client. The original complaint was made by the HCCC in February 2004. The NMB decision was reached in March 2006.

The effect of the HCCC prosecution has been to effectively place a prohibition on all future employment for our client and requiring an onerous amount of testing, (the nature of which is undignified and without a reasonable basis). It also requires our client to disclose to future employers his HIV status, a requirement that he would otherwise have no duty to reveal. Due to the considerable stigma experienced by people with HIV, the requirement to disclose has effectively limited our client's future employment. It has also placed him in the position of revealing his HIV status to persons not of his choosing.

In this matter, the HCCC demonstrated a lack of awareness of HIV and related illness. It has also demonstrated a lack of understanding of the stigma and discrimination faced by people with HIV. Our client had revealed his status in good faith with no legal duty to disclose. He was effectively punished for this action.

Case Study 2 – This involved a client who was sponsoring an applicant for a visa. The Doctor testing the applicant according to the Department of Immigration health requirements, disclosed the HIV test results to the sponsor without relevant authority and permission, and failed to provide or ensure provision of required post-test counseling and support.

The Doctor was performing the work in NSW and should have acted in accord with NSW health laws and regulations.

Upon a complaint to the HCCC the matter was referred by the HCCC to two other parties for their consideration. The HCCC did not complete an investigation and determine the complaint.

The law is straightforward and we provided legal parameters to the HCCC in the complaint. The HCCC failed to pursue this important issue of provision of medical care in a very sensitive area of practice.