

Declaration of rights: launch speech

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Full transcript of the speech by David Buchanan SC on Friday 18 November 2005.

I thank NAPWA for the signal honour it does me in asking me to launch the revised [Declaration of Rights for People Living with HIV/AIDS](#) [1].

It would be a bold person who declares that, before HIV/AIDS, no-one made the connections between human rights and health. But there is no doubt that one of the silver linings of the epidemic has been a vastly enhanced understanding of those linkages.

Why human rights?

HIV/AIDS is one of the few diseases capable of control partly through chemical intervention and partly by behavioural modification. And for both methods of prevention – indeed in respect also of disease control by treatment, care and support – the drivers of change are grounded in self-empowerment. People usually do what makes sense to them and what they have the power to do.

And, all things being equal, most people do right by others if right is done by them.

- If people have the resources to live their lives
- if people have control over their lives
- if they are treated with dignity and respect
- if their experience is drawn upon to ensure that right decisions about their lives are made
- if they can have the same fulfilling lives as everyone else ...

– these are the conditions under which public health has a fighting chance.

Returning the focus to HIV/AIDS, there is an abundance of evidence that in situations of violent conflict and where sub-populations are repressed, where human rights are violated, this disease becomes rampant. Where people have the resources and the power to control their own lives, public health outcomes are vastly improved.

Thus there arose the human rights-based approach to HIV/AIDS. If I can quote from a work edited by, among others, the late Jonathan Mann – a founding father of the human rights-based approach to HIV disease:

the human rights-based approach seeks to describe – and to promote and protect – the societal-level prerequisites for human well-being in which each individual can achieve his or her full potential.

Most actions taken in the name of public health are carried out by governments or government agencies at some level or another. Modern human rights are an effort to identify and agree upon what governments should not do to people and what they should assure to all. Thus it is that when recognising the dependency of health on societal factors and the linkages between these factors and the fulfilment of human rights, we are taking a human rights-based approach to health.

The sad part of it is that people don't have much time for a human rights-based approach to social problem solving. In this respect, Australia has a lot in common with countries considered to be run by highly authoritarian regimes. The 'human rights-based approach to HIV/AIDS' is a neat, short-hand term to describe a particular approach which is carved out of an otherwise largely medical model for addressing individual and public health

concerns. But at the end of the day, if there is one thing your average Australian shares with the State Law and Order Restoration Council which runs Burma these days it's a distaste for do-gooders banging on about human rights.

The pragmatic line which focuses upon the utility of the human rights-based approach without using the term "human rights" – or at least not very often – goes down much better with both governments and the masses.

But given we are here this evening to launch NAPWA's (revised) Declaration of Rights for People Living With HIV/

The Declaration explicitly recognises that there are multiple dimensions to human rights.

In the legal dimension, rights are expressed as legal norms (laws or judgments) and attract legal sanctions for their breach.

But they also have a moral or ethical dimension – where the obligations they impose are claimed to operate at a moral level.

And, critically for our lived lives, human rights comprise essential elements of our social and cultural way of arranging things. In the social and cultural dimension, human rights form the basis for a lot of what is pursued in political work and philosophical thought. Descending to the particular, human rights form the basis for working to improve individual and public health.

Let me briefly say something each of those dimensions.

Legal reasons

I am sorry to say that the legal basis for the Declaration of Rights is not as sound as it could be and as it should be. Don't get me wrong – there is a solid foundation for the rights identified in this Declaration in international law, in a number of international legal instruments and in international health documents such as the Ottawa Charter and the International Guidelines on HIV/AIDS and Human Rights. However, except to the extent that it has been adopted as part of Australian law, international law is not enforceable in Australia. We have in Australia a number of disparate domestic laws which protect and advance the rights of people with HIV. Anti-Discrimination laws are the most obvious. Examples of others are –

- public health laws (or some of them)
- the *Therapeutic Goods Act*
- the *Health Insurance Act* (Medicare)
- the medical practitioners statutes
- occupational health and safety legislation
- the provisions of illicit drugs laws which allow for licensing of needle syringe programs.

However, Australia is steadily falling behind comparable industrialised countries. Others have or are governed by a human rights Act or a Bill of Rights – a basic statute, operating like the our Commonwealth Constitution. A Bill of Rights or a Human Rights Act would set out fundamental standards for the conduct and laws of each State and Territory and for the Commonwealth. There are countries like South Africa and Venezuela which embody health rights into their basic human rights statute. In Venezuela's case, it has led to a Supreme Court decision requiring that country's government to provide anti-retroviral treatments to all people with HIV. In South Africa, litigation to accord people with HIV/AIDS the basic right of access to treatments is ongoing. In India, on the basis of broad general rights in that country's Constitution, the courts have declared the sacking of people who test positive to be unlawful.

However, a human rights statute is opposed by the powerful in Australia. I leave to another day a critical analysis of the spurious reasons advanced for that opposition.

Ethical reasons

But there are sound reasons too why we should ground our approach to the human rights of PLWHAs in [ethics](#) [2] (*In clinical trials*) *The process of determining that a proposed clinical trial conforms to a wide range of moral, scientific and ethical standards, to ensure that participants in the trial are not abused, mistreated or unfairly taken advantage of. Before a clinical trial can go ahead, it must be given approval via an independent ethics process.* There are people – many in positions of power – who would deny positive people the same human rights as those to which they regard themselves as entitled. Those people often employ arguments couched in the language of morality –

- ‘it would be immoral to prescribe heroin for heroin addicts’
- ‘it would be immoral to give same sex couples the same recognition under the law as heterosexual couples’ (unless you’re the partner of a person suspected of terrorism)

In my view, we should deny our political enemies the moral high ground. Firstly, they are not entitled to it. Secondly, it is immoral to deny people the rights to which they are entitled as people living with HIV/AIDS.

Of course there should be an ethical framework for all the standards by which we live our lives. I would suggest that for everyone here this evening, we already have such a framework even if we haven’t tried to articulate it and write it down. Which is the point of this Declaration of Rights. You won’t find much in the Declaration that you disagree with. But particularly in a disease context where the mere fact of infection or risk for infection or association with the infection is stigmatised, it is important to *express* exactly how people who are infected or affected by HIV should be treated. It is important to express the fundamental right of people living with HIV/AIDS to self-determination.

The fact that others might not have such an ethical framework or might disparage it does not tell us much about whether we should adopt an ethical approach to the way we live our lives and treat others. If we think we have an ethical approach to life which is superior to that of other peoples then we should put our money where our mouth is. We should adopt ethical principles for living and for decision-making. We should say what those principles are. And we – the whole of the community that makes up Australia – should be vigilant to cross-reference our work and the way we live our lives against those principles.

Pragmatic reasons

I want to go back, to draw again upon something said by Jonathan Mann.

Back in 1991, Mann identified four reasons why human rights must be protected in the context of HIV/AIDS:

- because “it is right to do so”;
- because preventing discrimination helps ensure a more effective HIV prevention program;
- because social marginalisation intensifies the risk of HIV infection; and
- because “a community can only respond effectively to HIV/ AIDS by expressing the basic right of people to participate in decisions which affect them.”

Mann concluded that it is –

essential and inevitable that we look to the insights and guidance of human rights, ethical and humanitarian values as we consider how to move ahead and advance in policy and programs (related to HIV/AIDS).

What you might have noticed is that three of the four reasons given by Jonathan Mann have a distinctly pragmatic tone. What Mann cast light upon was the linkages between according human rights and improved health outcomes. The lesson he taught was that *human rights work!*

I can remember my own first dawning of this lesson. Before the mid-1980s, as a lawyer I used to be involved on the fringes of Aboriginal rights work. As a white person who enjoyed the fruits of European colonisation of this country, it nevertheless seemed obvious that if Aboriginal people were treated better, were given back their identity, if they were honoured rather than stigmatised for being the original inhabitants of our country then their social and material situation should improve. But there's nothing like lessons learned at home.

By the mid eighties, affected by HIV/AIDS as I was by reason of my homosexuality and gay identity, it was not at all difficult to muster the arguments in favour of laws to protect confidentiality of people testing for HIV and to protect against discrimination people who had or were at risk for HIV infection. In the early days of an epidemic which has been with us now for over 2 decades, we knew from gut instinct what would work and what wouldn't work. And in the fundamentals of a strategy to deal with HIV, we were right. It must also be acknowledged, of course, that we were dead lucky to have bipartisan political support from intelligent people for our preferred approach – participation in a partnership with the various sectors which would work on this disease.

But I have to confess that it took a number of years – until probably the early 1990s – before I came to appreciate that the evidence for the validity of the human rights-based approach was there staring us in the face. It literally amazed me that HIV disease was clearly demonstrating that there are practical, dramatically improved outcomes when the human rights of people with or affected by the [virus](#) [3]A small infective organism which is incapable of reproducing outside a host cell. were protected. And we could see these dramatically improved outcomes because the contrast with places where human rights were not accorded people at risk of or with HIV became stark. It was horrifying really. It still is.

You don't need from me a lecture on the connections between human rights violations and the terrible toll in AIDS

- where people at risk or with HIV are given a measure of control over their lives and are involved in decision-making about the disease in their communities,
- where stigma is reduced and people with HIV don't need to go underground,
- where abuses and violations of people's rights generally are reduced,
- where condoms are available,
- where kids are given information on HIV transmission,
- where men, women and children who have lost their partners and parents to HIV are supported,
- where sustainable access to treatments is available.

Right versus duties

It is often said that the flip side of rights is duties – that for every right there is a corresponding obligation to protect or at least not to transgress that right. As a statement of general principle this can be readily accepted. We would all say that the rights inherent in HIV positive people bespeak a bundle of duties on the part of those to whom we look for our rights. Thus, positive people have a right to participate in decision-making about HIV/AIDS policy. Decision-makers have a duty to involve HIV positive people in decision-making around HIV/AIDS.

But I don't want to brush the demons under the table – let's drag them out. In public discourse about public health and specifically HIV/AIDS, the correlation is sometimes said to be between the rights of PLWHAs and their duty not to infect others.

I would question that necessary correlation. A so-called "duty" not to infect others is essentially no more than the duty which everyone has – all things being equal – not to harm others. There is no morality in an HIV positive person either recklessly or deliberately infecting others simply because that person's rights were infringed – even if the person to be infected had been the source of the original infringement of the positive person's rights. There is no vindication of human rights in spreading harm around.

Human rights are not baggage to be discarded at the first breach of a duty and duties are not baggage to be discarded at the first infringement of a human right.

But this is not to deny the synergy between rights and duties – even between rights and unrelated duties. On the contrary. In modern times, we have a much clearer understanding of these relationships. We now know, for example, that a person who suffers abuse as a child is at higher risk to abuse others when themselves in a position of power over others.

I would argue that if those of us with the duty to accord HIV positive people their rights actually perform those duties there is no doubt that the impact upon people's lives would directly affect the likelihood that duties not to harm others would likewise be observed. It's all about respect. If you respect me and show that you respect me, the chances are that I will show respect for you.

People living with HIV/AIDS don't need sermons about avoiding harm to others. The perception that positive people are in need of laws criminalising disease transmission tells us more about the stigma attaching to HIV than about actual disease transmission risk.

At the end of the day, if the State, if people in groups and if people as individuals take a social justice approach to people with HIV/AIDS, then a reduction in disease transmission will be but one of the social and public health benefits which ensue.

It's all part of a package.

The revised Declaration of Rights

NAPWA's revised Declaration of Rights for People Living With HIV/ AIDS is an important part of that package.

Drafted by Claude Fabian and Gabe McCarthy, the original Declaration was adopted in 1993. It was in part inspired by the Denver Principles. In June 1983 in Denver, Colorado, a movement of people living with HIV emerged at a national medical conference on AIDS. They protested their exclusion from the planning of workshops relating to AIDS. The 'Denver Principles' adopted at that conference called for those living with HIV to be supported when they opposed AIDS-related stigma and discrimination. The Principles also stated that people living with HIV should –

be involved at every level of decision-making ..., serve on the boards of directors of provider organizations, and participate in all AIDS meetings with as much credibility as other participants, to share their own experiences and knowledge.

Shortly after the adoption of the original NAPWA Declaration, the GIPA principles were first publicly expressed. The term was used in a Declaration that was signed by representatives of 42 countries at the 1994 Paris AIDS Summit which undertook to –

fully involve ... People living with HIV/AIDS in the formulation and implementation of public policies ... (and to) ... support the greater involvement of people living with HIV/AIDS (GIPA).

The principles of GIPA were later reinforced by the UNGASS Declaration in 2001, signed by almost all members of the United Nations. And in 1998 there were promulgated by the United Nations the International Guidelines on HIV/AIDS and Human Rights.

We all know that a lot has changed in the lives of HIV positive people in Australia since 1993/1994. The advent of

At the same time, however, despite the global acceptance of the GIPA principles and the International Guidelines on HIV/AIDS and Human Rights, it has become clear that, even when implemented, GIPA by itself would not bring about much of a change in the lives of people living with HIV/AIDS. In many countries, representation on official committees has not necessarily translate into a significant vindication of the rights or influence of positive people.

A sharper focus on the rights of HIV positive people is also needed.

It was in that context that, at NAPWA's biennial conference in Cairns in 2003, when NAPWA's 1993 Declaration of Rights was scrutinised, it was considered that the document was somewhat dated and in need of revision.

As many of you here know, NAPWA then embarked upon a program of broad consultation, across all portfolios and involving all State and Territory organisations. The drafting committee then produced a substantially revised Declaration. Considerable thanks are due to the drafting committee –

- Mark Cattell and John Cummings (NAPWA's past and present Legal Portfolio National Convenors)
- Michelle Tobin
- Kirsty Machon (NAPWA's health policy officer)
- NAPWA board member Bernard Kealey, and
- NAPWA President, Gabe McCarthy.

The revised Declaration is structured differently from the 1993 document. It has a substantial and considered preface. It is framed in terms of declared human rights in some twenty-one areas of the lives lived by people living with HIV/AIDS. Each of the declared rights is a touchstone for the proper, ethical approach to according positive people their entitlement to a fulfilling and fulfilled life.

It gives me great pleasure to launch the Declaration of Rights for People Living With HIV/AIDS!

- [HIV and the law](#)
- [human rights](#)

Links:

[1] <http://www.napwa.org.au/?q=node/481>

[2] <http://www.napwa.org.au/glossary/term/498>

[3] <http://www.napwa.org.au/glossary/term/125>

[4] <http://www.napwa.org.au/glossary/term/96>