EUTHANASIA

Right legislation: Wrong jurisdiction?

Chips Mackinolty

Extract from a written statement to the the Senate Committee on Legal and Constitutional Affairs Inquiry into Euthanasia.

Editor's introduction

The passage of the Euthanasia Laws Act 1997 (Cth) through the Senate was as vivid an illustration of representative democracy at work as we're likely to see for some time in Australia.

The debate and vote were preceded by an inquiry by the Senate Legal and Constitutional Affairs Committee which attracted an unprecedented 12,577 public submissions. The Committee's Report gives particular prominence to the oral evidence of long-time Darwin resident Chips Mackinolty, who had previously been commissioned by the Northern Territory Government to conduct an education program in Aboriginal communities about the Rights of the Terminally Ill Act 1995 (NT) (ROTI).

The program's Aboriginal Steering Committee instructed Mackinolty to record Aboriginal views about the ROTI and relay them to the Government.

Mackinolty and his team proceeded to conduct 21 community meetings across the Territory with some 900 Aboriginal people from approximately 100 communities between June and October 1996. Men and women met separately, and interpreters were used at each meeting. Mackinolty estimates that about 6% of the adult Aboriginal population of the Northern Territory participated directly in the program.

The results were virtually unanimous: every one of the meetings was strongly opposed to the ROTI, and Mackinolty reports that of the 900 participants, only two, in private comments, expressed views supportive of the legislation.

Mackinolty's Senate submission, which is published below, is impressionistic rather than academic in form, but the impression he had received was overwhelming. As a personal supporter of euthanasia, he had some misgivings about disseminating arguments which he knew would be enthusiastically taken up by conservatives as fuel for their campaign against the ROTI. And, indeed, this is precisely what transpired: Mackinolty has attracted criticism in some progressive circles for playing into the hands of the Lyons Forum. But his decision to speak out was driven by a firm belief that the views of the Aboriginal community, whose members comprise a substantial majority of the Territory's permanent population, must be given due and proper weight. • RG

The aim of the education program was to inform Aboriginal people of the nature and content of the ROTI legislation. It was not to 'take sides' on the legislation one way or another, but to inform. Nevertheless, we undertook, as we moved around the Territory, to relay any concerns people had back to Northern Territory Health Services (the department). The major emphasis was on delivery of the program to remote Aboriginal communities, though major centres were also covered.

On taking the contract, the department and myself were of the view that, given appropriate educational delivery and content, people would

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understand what the legislation was about, and that the fears that had been expressed in some quarters of the media, would be sufficiently allayed such that Aboriginal Territorians would deal with the legislation in much the same way as they do others.

The voluntary nature of the legislation would ensure that people wouldn't fear a law which, by its nature, did not have to be activated unless an individual chose (though the notion of a 'voluntary' law also proves problematic, see below).

At one level, I am confident that among the 800 or so people we spoke to in face to face education sessions, such knowledge was understood at the level of factual, objective information. A number of communities took on further education work among their people at the family/clan/community level; and feedback from many of the sessions was positive in terms of peoples' understandings of the process.

However, for reasons I will explain, I am not convinced that acquiring objective knowledge of the contents of the ROTI legislation had any significant impact on Aboriginal knowledge and perceptions of sickness and health, life and death. For this reason, it is my personal view that the existence of the ROTI legislation presents a continuing threat to the health and wellbeing of many Aboriginal people in the Northern Territory.

Two cosmologies: clashing? — or not meeting at all?

It has been claimed in some quarters that rejection of the legislation can be attributed largely to unscrupulous manipulation on the part of Christian churches operating on Aboriginal communities. The inferences from this seem to be that Aboriginal people either should not have the freedom of choice to embrace Christianity, or that they are too stupid to see through being manipulated. I find both inferences offensive and wholly inaccurate.

I strongly suspect that the Christian churches present on many Aboriginal communities were not as influential and successful on this issue as they might have liked. As noted in my reports to the department, rejection of the ROTI legislation was just as strong on communities not heavily influenced by Christian churches. It is my firm view that it is traditional religion and law that has been the overwhelmingly dominant factor influencing Aboriginal peoples' rejection and fear of the ROTI legislation.

Where Christian views certainly played a part on those communities that have an enduring attachment to one or other of the churches, there is no doubt in my mind that adherence to traditional views about life and death have been the principal motives behind Aboriginal attitudes.

After the program was in place for some weeks, it was my initial view that there were two widely differing world views or cosmologies at play in the debate on euthanasia on Aboriginal communities; and that these two cosmologies were clashing on the issue. Over time, I have come to the conclusion that in fact these two cosmologies just weren't meeting at all.

To put it in basic terms, and I make no apology for oversimplifying very difficult concepts, in Aboriginal cosmology the notion of 'natural' death applies only, perhaps, to the extremely old person. In all other cases, cause of death lies in a complex interplay of sorcery, payback and/or transgression of the law.

Thus, although the 'cause' of death might appear to non-Aboriginal people to result from trauma (e.g. a road accident) or disease (e.g. a heart attack or cancer), Aboriginal people would look beyond such apparent 'causes' to determine whether the person died from sorcery attacks, vengeful spirits, from breaking the Law and so on. In that light, things such as cancer or a vehicle rollover are merely 'agents' by which that person died — not the 'cause'. The nearest thing I can liken it to is a post mortem: on many occasions bodies will be inspected by senior ritual leaders to determine who or what 'caused' or 'made' someone die.

In light of this, the somewhat sensationally publicised fears about 'the euthanasia needle' miss the point, if you'll excuse the expression. It is not the needle as such that people fear, it is the capacity of the 'euthanasia needle' to be used as an agent of death — particularly by sorcerers — that has engendered such universal distrust, and widespread demands that the euthanasia drugs not be kept on communities; that community clinics and staff be prohibited from practising euthanasia; and for the legislation to be repealed.

I know this is a difficult area to understand, dealing as it does with unfamiliar notions such as sorcery, which western 'science' would dismiss — if not ridicule — as superstition. I make no comment about peoples' belief systems suffice to say that such systems are deeply embedded in various world views — Aboriginal and non-Aboriginal — and are an integral part of peoples' lives. Peter Sutton, one of Australia's leading anthropologists, was quoted thus last year:

> Sorcery is one of the most enduring bits of Aboriginal tradition and culture ... It's not just superstition. It's totally integrated with politics and the need for social control. People are not politicising this issue [euthanasia] in the media, they've always politicised death.

So imagine, if you can, the fearful power a sorcerer might wield through the 'agency' of euthanasia: being able to 'make' a white doctor in Darwin, say, kill someone through the 'euthanasia needle'.

The views gathered in the course of the education program emphasize Sutton's statement about the durability of this belief system, and can be found in the literature. For example, Janice Reid, in research carried out in the late 1970s in north eastern Arnhem Land confirmed that there had been no fundamental change in people's attitudes over the 40 odd years since T.T. Webb wrote on the issue in the same general region in the 1930s. Indeed, Reid suggested that traditional attitudes had possibly strengthened over that time as a response to colonialism. The attitudes we found, 60 years later, again in the same region, revealed no diminution in these cultural attitudes to life and death.

So, there is a very simple solution for people to avoid the perceived threat: avoid clinics and hospitals so as to minimise chances of having to confront this new threat in the armoury of the sorcerer.

When this issue was raised by me with the Health Department, they did the only logical 'scientific' thing: they inspected clinic statistics to see if there had been a dropping off of clinic use. As the Northern Territory submission suggests, there has been no lessening of clinic use according to available statistics.

I do not argue this, except to point out that even with the best statistics in the world —and the department has acknowledged elsewhere their figures are not as good as they would like — statistics can only measure what has happened in the

past, not what will happen in the future. Furthermore, no matter how good the data collection method is, statistics will not reveal the rates of non-presentation or late presentation, or the extent to which these factors may or may not have affected the course of an illness.

There has been widespread research and anecdotal evidence to suggest a reluctance on the part of many Aboriginal people, many of whom are in high risk categories, to present at clinics or go to hospital — even before the introduction of the ROTI legislation. It makes perfect sense: why go to a place where people die?

Since that time, anecdotal evidence to the effect that people are not presenting, or delaying presentation or treatment, because of fears about euthanasia has been reported to us on many communities; and indeed three deaths 'caused' through the 'agency' of euthanasia were reported to us, even before the legislation came into effect.

There are two potential consequences of people's reluctance to present at clinics or go to hospital in a timely way because of these fears.

First, that in the event of say a relatively minor outbreak of influenza, if significant delays in presentation for treatment occur, there is a much higher possibility of potentially fatal complications such as pneumonia occurring. There is little need to remind the inquiry of the fact that Aboriginal people have far poorer health outcomes that the rest of the population.

Second, there is potential for the reputation of Northern Territory Health Services and many local clinics to be placed in jeopardy. Aboriginal health workers, in particular, informed us that the existence of the legislation, and the fear of it, made their positions difficult to maintain and one, unconfirmed, said that he would quit if the legislation was introduced. It was not just a simple issue of lack of willingness to be involved in the legislation, which they are not legally obliged to be in any case, but that they might receive 'blame' for deaths through the agency of euthanasia on communities or at hospitals, and be subject to payback.

A number of non-Aboriginal nursing staff and doctors have also expressed fears to us about their positions, their standing in communities, and their abilities to perform their work properly. Again, the impact of this on the health outcomes of Aboriginal people is difficult to gauge, but certainly makes a difficult task harder for the department and its employees.

It is worth noting, in this context, that private Aboriginal-owned clinics have demanded, and received, written undertakings from staff that they will not participate in euthanasia so as to reassure patients that these clinics are 'safe' to attend. Legal and other reasons preclude this occurring in government clinics, and an attempt to amend the ROTI legislation to exempt Aboriginal community clinics from participating in euthanasia failed to pass the NT Legislative Assembly.

None of the aforesaid should imply that Aboriginal people do not want to use and understand Western medical services. Along with traditional medicine, Western medicine is seen as valuable. The success of the Aboriginal Health Worker system and the establishment of Aboriginal community-controlled health centres is evidence of that. However, it does indicate potential problems down the track for the Territory Health Services and community clinics, as well as implications for Aboriginal health education.

Aboriginal versus non-Aboriginal Law

Some commentators, with greater or lesser knowledge, have suggested that traditional Aboriginal Law in the past either sanctioned or was silent on the issue of euthanasia, and that therefore the current ROTI legislation is acceptable to or does not offend Aboriginal Law.

However, one of the most widespread and persistent views expressed to us was that the ROTI legislation is 'against Aboriginal Law' and that, conversely, palliative care is the 'Aboriginal way'. In its most graphic form we were told '... it might be all right for that man in Darwin to kill his mother, but we don't do that here!'

From our experience it would seem, therefore, that whatever may or may not have been part of the Law in the past (and it is doubtful many people were asked about euthanasia until recently), opposition to euthanasia at present forms a part of the public ideology of Aboriginal Law.

There is widespread acceptance among Aboriginal people that there can be 'a time to die' and I have had direct and indirect experience of people refusing food and going off into the bush to die.

However, virtually all the people we spoke to expressed complete abhorrence at the notion of another person, such as a doctor, actively assisting in such a process, and this was consistently expressed in terms of it 'being against the Law'.

The 'Law', of course, is not codified in the way that non-Aboriginal Australia codifies or describes its laws but, in simple terms, Aboriginal people would regard the action of assisting suicide as a form of unsanctioned killing, and therefore illegal. By extension, the Aboriginal view as expressed to us is that the Government has broken Aboriginal Law by legislating to sanction such killings, and this is seen as a threat to Aboriginal people and Aboriginal Law.

There are, I believe, deeper problems at play here. Aboriginal people believe, as has been often noted, that they are subject to 'Two Laws' which often conflict: traditional Aboriginal Law and non-Aboriginal law. In the case of the latter, Aboriginal experience of this has largely centered on the criminal law and one of the fundamental precepts of the criminal law (and indeed traditional Aboriginal Law), is the obligation to obey the law or face sanctions.

The ROTI legislation appears to contradict this precept insofar as it can only be 'activated' through the voluntary choice of an individual — beyond which it is largely a law that regulates the actions of doctors and other participants in the process. Furthermore, the individual can — right up the end — voluntarily deactivate the process of the legislation. We encountered widespread disbelief that a law on such an important issue could be framed in such a fashion, and suspicion that the ROTI law might now or in the future be activated by individuals or the state on behalf of others.

As noted above, palliative care was universally supported by Aboriginal people as the way people have traditionally looked after their people under their Law.

Individualism versus collectivism

One of the great ironies of the ROTI legislation is that while its original drafting and subsequent amendments were designed to maximise and protect the role of the individual in the equation — it is this aspect of the legislation which most clearly transgresses and offends against Aboriginal ideas about civil society, which is collectivist in nature.

Indeed, many we spoke to were astounded that such a fundamental decision about life and death could, or should, be made without reference to the immediate family and extended relationships or others with ritual relationships to the person involved.

It is not that Aboriginal people suffer less in terminal illness, nor that they wish less relief from pain, but that ways of dealing with death are not, in general terms, alienated from the group. To make such a profound decision as volunteering to have one's life terminated via an external agent without participation by the extended group, and indeed with legislative protection and sanctions against being directly influenced by people other than the volunteering individual was seen as an anathema — and yet again, against the Law.

The majority view?

One of the most persuasive arguments in support of legislating in favour of voluntary euthanasia is that, in Western countries such as Australia, there has been substantial consistent long-term public support for such legislation, and that politicians should not stand in the way of such overwhelming public opinion. Figures of 70% support are often cited.

Apart from the populistically superficial nature of this argument, it is doubtful that the same could be said in the case of the Northern Territory. From our experience it would be my estimate that at least 90% of Aboriginal people in the Territory would be opposed to the legislation — quite probably higher. Given the fact that 22% of the Territory's population is Aboriginal, overall support for the euthanasia would be substantially less than that for the rest of Australia, possibly lower than 55%.

Conclusion

I have had the privilege of working with Aboriginal people for 25 years in four states, including 16 years in the Northern Territory. In that time I have been involved directly and indirectly in the funerals of perhaps 150 or more people known to me personally. In only two cases could it be realistically said that they have died of 'old age' in the normally accepted — to non-Aboriginal people — sense. Many more of my friends are currently facing premature death — largely as a consequence of their Aboriginality. It is a death toll that reflects the fact that Aboriginal people live on average 20 years less than non-Aboriginal people, and die prematurely of illnesses more characteristic of the Third World than suburban Canberra. It is a death toll that is reflected in the almost permanent state of mourning across regions of the Territory as people die — and the fact that mortuary rites dominate over other ceremonial life.

I personally support my having access to euthanasia — but not in the Northern Territory. It is arguably the right legislation — but certainly the wrong jurisdiction. My reasons for this are both simple and complex.

Whether the legislation is good or bad for us, as whitefellas within our own cosmology, is immaterial. I believe the very existence of the legislation poses an unacceptable risk to the health of Aboriginal Territorians who may delay or refuse to access health care because of fears they have of the legislation. Those fears are deeply embedded in Aboriginal world views. Put simply, it has the potential to lead to premature deaths amongst a group of people whose life expectancy is already unacceptably low.

Due to complex ways in which Aboriginal belief, social and cultural systems do not 'match' those of non-Aboriginal Australia, external reassurances about the 'voluntary' nature of the legislation will be unlikely to lessen the very genuine cultural misgivings and fears Aboriginal people have about the existence of the Act. While this law remains on the books in the Territory, it will continue to pose this threat to Aboriginal health.

This threat will continue for a very long time to come if Aboriginal world views about health and illness, life and death persist — and the evidence to date is that those world views have already persisted for a substantial period despite long-term contact with non-Aboriginal world views. This persistence of such world views is not amenable to 'education programs' in general — let alone the kind contemplated and carried out as part of the ROTI legislation education program — no matter how much support and good will is afforded by such a program. People, no matter what their cultural background, do not 'unlearn' their world view so easily.

I hope I make clear that I am not saying that Aboriginal people will be killed through any slippery slope mechanism whereby the weak may be vulnerable. Indeed the language/interpreter requirements of the Act make it all but impossible in the next half decade or so for the vast majority of Aboriginal people to access the Act, even in the unlikely event that they might want to. For Aboriginal people, a 'slippery slope' commenced prior to the existence of the Act.

But I do believe that there are very real risks to the health of Aboriginal people, by virtue of the existence of the legislation: it's what people believe about the legislation, not what may actually be contained within it. Frankly, I do not think Aboriginal people need another potential 'agency', let alone 'cause', of death.

I believe the 'debate' over euthanasia legislation has not come to grips with the reality of the jurisdiction in which it has been enacted — one in which such a high percentage of the population has such a radically different world view from the general population. The 'debate' has concerned itself entirely with either Western ethical/moral arguments, or arguments over the 'rights' of the Northern Territory to make legislation for itself without interference from the Commonwealth, that is, a 'states' rights' argument. Both lines of argument centre solely on a Western world view; both ignore Aboriginal world views.