

Report to Aboriginal Reference Group: *Rights of the Terminally Ill* Act Education Program 28 June 1996

- 1 As of today, the central Australian leg of Stage 1 of the education program has been completed. This has included two trips to Tennant Creek, and sessions at Ntaria, Utopia, Apatula, Papunya, Yuendumu, Mutitjulu and Alice Springs, with these meetings being attended by representatives and health workers from a large number of other communities and outstations. Thus far eight out of 25 community meetings have been completed.
- 2 Deaths on communities have led to some problems in delivery so far. This has been circumvented by re-scheduling some communities attending different sessions. However, next week's trip to Groote (which takes in Numbulwar, Bickerton, Angurugu, Umbakumba and Bartalumba Bay) is to be postponed to a date to be set because of a recent death. Similarly, a visit to Elliott will have to be re-scheduled.
- 3 Preliminary work has started on gathering language centres/translators together to start work on the second stage of the program. I am hopeful IAD will be able to start on central Australian languages next week.

There has been concern expressed in some quarters that people "reading" the language material for the audio tapes would be reluctant to do so because of fear of being identified with the legislation. I have made arrangements with the Australian Broadcasting Corporation to get access to facilities there to distort voices so they cannot be identified.

Comments and feedback

- 1 The level of fear of and hostility to the legislation is far more widespread than originally envisaged. For example, we are aware of at least two community-wide anti-euthanasia petitions that are being circulated. While it was expected that Aboriginal people out bush would be opposed, and would be highly unlikely to avail themselves of the Act, opposition to its existence must be viewed as near universal — which makes one wonder about the public opinion polling that suggests high support among the NT public for the legislation. One imagines that phone polling doesn't get to too many Aboriginal people.

- 2 One central Australian community, after hearing out some of the education program, became extremely angry at the legislation's existence ("... it might be all right for that man in Darwin to kill his mother, but we don't do that here!"), and asked us to leave. One health service boycotted an initial meeting (though later sent a representative to a subsequent meeting), and has required their medical staff to sign undertakings that they would not participate in the legislation. One non-Aboriginal clinic supervisor — extremely hostile to the legislation — actively discouraged health workers from attending. It has been expressed to us by a number of individuals that euthanasia is seen by some as a further method of genocide of Aboriginal people.

People are extremely angry that they were not consulted about the legislation in the first place (and were hardly mollified when it was pointed out that whitefellas were not really consulted, either). There has also been the point made that the education program should have been carried out in toto before the legislation came into effect (see 6 below).

- 3 Conversely, there has been genuine interest from health workers and community leaders in finding out exactly what is in the legislation (albeit with a sense of trying to work out what these crazy whitefellas are up to now!). The "two roads" diagram has proved a very successful approach (see attached diagram) as has the flow charts. There have been a number of requests for the coloured version of the chart to be made available to all clinics: this may be possible depending on budget and the future of the program (see below).
- 4 As expected, there has been considerable interest in Palliative Care, which has been seen by all as "the Aboriginal way". In our session with Palliative Care mob prior to the delivery of the program we discovered they are delivering palliative care services to a significant number of clients out bush, especially in the Top End (perhaps the Minister should be made aware of this, to counter some claims that it is only the euthanasia option that is being touted around the traps).

As a result of our work so far, a Palliative Care worker travelled from Alice Springs to Tennant Creek and was well received — and identified an eligible client in that town. They are due to deliver a week long seminar to health workers in Tennant in September. There have been strong requests for material on Palliative Care to be translated into language (see memo to Wendy Hunter).

- 5 There is a continuing philosophical problem apparent throughout this process, and that is related to widespread Aboriginal beliefs about cause of death, that is, that there is no such thing as natural death and that deaths are caused by external agencies such as sorcery, payback, transgression of the Law etc. In simple terms this means that those things non-Aboriginal people may identify as "causes" such as cancer, HIV-AIDS, car accidents etc are not seen as such — even by long term Aboriginal Health Workers.

In some senses, this makes the whole discussion of euthanasia pretty academic. In others, though, it makes the whole issue of the role of medical and health staff, and mechanisms such as injection, extremely problematic as these personnel and their tools of trade may now be seen as agents of sorcery/payback, with consequent fears being engendered.

This has the real potential of setting back the work of Territory Health Services and health centres in gaining confidence and trust of their clients by years. We have been told of direct cases already where people have been reluctant to present because of fears of the legislation, and of cases where deaths have been ascribed to euthanasia already having been carried out.

Obviously we have been at pains to emphasise the importance of *not* fearing injections/hospitals/clinics etc as we have been moving around, but have no confidence that this information will be believed in the short term.

- 6 Allied to this has been the fact that we are carrying out the education program in large part after the legislation will come into effect in a context of escalating public controversy about its introduction, including that over the legal challenges/potential Federal overriding of the legislation. Frankly, this is making it almost impossible to deliver the program in the "low key" way we had hoped.

I have been heartened by media approaches to our work in that they have, at my request, left us alone while maintaining an interest in it. In particular, I have been pleased with the ABC TV's approach: at my request they have stopped using images of injecting needles and drips in the context of reporting news about the controversy.

I have given an undertaking to various media bods that I would give a briefing in about mid-July, both on and off the record, on the program. I would be advised on this by the Minister's office, the Reference Group and the Department about this, especially with regard to timing. I would feel comfortable with mid-July, and would like some members of the Reference Group to participate if they felt comfortable with it.

By next week I should have copies of initial reports from communities back from the team and will be able to report on this more extensively.

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