

Report to Aboriginal Reference Group: *Rights of the Terminally Ill* Act Education Program 23 July 1996

- 1 As of today, we are three quarters of the way through Stage 1 of the program — the delivery of information to community leaders and Aboriginal Health Workers across some 25 community centres in the Northern Territory.
- 2 Three communities have indicated that they do not wish to receive the program until after the Supreme Court has delivered its verdict — and perhaps until after the Federal Parliament has met to pass/not pass legislation overriding the NT legislation. The rationale for this is that they do not want the confusion of having received one set of information that may be superseded by other developments.
- 3 We are having continuing problems with re-scheduling due to local community problems/deaths etc. For the most part we are able to pick up the changes but it may be that a few communities will be “left over” and will have to be picked up at the end of the process.

Further comments and feedback

- 1 I would love to report some sort of epiphany on the road to the ROTI legislation, but it just hasn't happened. If anything I feel a bit more gloomy about the whole process and its impact on the Health Department.
- 2 The education team have asked me to forward three main points from their work thus far:
 - The greatest fear and reluctance about the legislation would appear to be coming from Aboriginal Health Workers themselves. They are concerned that their position within their own communities has been or might be irreparably damaged by the existence of the legislation (one said he was resigning as a result of the legislation). At times this has been expressed as hostility to the education team (allayed afterwards but not pleasant nevertheless!); at times as a refusal and/or reluctance to attend sessions — especially in contexts where senior people from their community have expressed opposition to the legislation.

- There is continued interest in finding out more about Palliative Care (see previous reports) — including information in language as that is more easily accessible by older people who are more likely to be worried about euthanasia and conversely re-assured with news of Palliative Care.
 - There is an un-met demand for accessible and understandable information and explanations about why people have died — especially when it has happened at hospitals in main towns. I believe this reflects the tensions I have previously outlined in reports on peoples' views about causes of death versus "medical" explanations.
- 4 It would seem to me that the process so far has revealed policy implications/problems for the Department — some of which were anticipated, some not. I think the first aspect of the problem is that feelings about the legislation are far more widespread than originally envisaged, that is, they are **not** limited to those communities who have strong "Church" followings; the second is that education programs on a variety of health issues have only been partially successful over the years because of different world views about the nature and processes of disease and health. To quote Catherine Berndt:

*There are still some officials who claim that if Aboriginal people knew more about the nature and transmission of disease (for instance), they would accept the total package available to them through medical and health care services, a package that includes definitions and causation statements about prevention as well as about curing and healing. More recently, another kind of orientation is emerging in "community health" programmes. It goes beyond narrow definitions of health and sickness and tries to take into account the whole environment, physical and social. In that respect, it is moving closer to traditional Aboriginal views on the subject. (Berndt, C, "Sickness and Health in Western Arnhem Land: A Traditional Perspective", in *Body, Land & Spirit*, Reid, J, UQP, 1984, 121)*

The "problem" is the Territory Health Services' successes in developing a more holistic approach as described by Berndt is compromised by a "package" that now includes euthanasia, with all its differing interpretations I have previously reported on. While at the end of Stage 1 of the education program we will have spoken face-to-face with close to 5 per cent of Aboriginal adults in the Territory, more often than not through interpreters, this will not preclude people simultaneously holding different and at times apparently contradictory understandings of euthanasia (for example, that euthanasia is a voluntary action undertaken by people for whom it is culturally acceptable such as whitefellas; but that it may simultaneously be a possible agent for sorcery or payback). This has enormous potential to compromise and/or damage the reputations of Territory Health Service staffers from AHWs to doctors.

- 5 As I have mentioned in meetings with the Reference Group and with the CHO, there is potential for the Territory Health Services to rescue its position with the positive "spin" of Palliative Care Services. Certainly I can envisage positive messages pushed out on this basis — but it carries with it certain dangers, especially if the resources are not available to meet current and/or future demands for such services. It would only increase suspicions and hostility if "warm and cuddly" messages were presented without any sort of back up with resources: notwithstanding what Palliative Care proponents assert about the benefits of such services, it is universally acknowledged that it is early days in developing the program.

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