

National Advisory Committee on Health and Disability Services Ethics

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The Minister of Health for New Zealand agreed in mid 1994 to accept in substance, most of the recommendations of the Interim Task Group on Health and Disability Services Ethics, which she had previously convened. A significant change from the existing system of ethics review, was the addition of a National Advisory Committee on Health and Disability Service Ethics which will, through the rest of this short report, be known as the National Ethics Committee. The system upon which this had been built was already quite a strong system, in which there were regional ethics committees in most areas of New Zealand, none of which were entirely linked to any health service provider. The committees were half lay and half professional, and reviewed both research and clinical ethical issues.

This meant that in addition to a monthly diet of research protocols, the committees quite often had decisions to make about policy matters such as "Do-not-resuscitate orders", managing

decisions at the end of life, new treatment protocols, and so on. The mixture of lay and professional members meant that the committees could not be considered to be dominated by clinicians or researchers, as the lay members were significantly empowered by constituting at least half of each committee. The chairperson of each committee was also a lay member.

In addition to this basic framework for local ethics committees, there existed a networking arrangement, whereby the chairpersons of the local ethics committees, and on occasion, other members, would meet as a group, usually in Wellington. This informal meeting of chairpersons generated a certain amount of uniformity and the opportunity to discuss issues which were challenging different committees, so that progress, rather than being piecemeal throughout the country, could be reasonably rapid and concerted

without imposing too much on the autonomy of the local committees. This arrangement worked well in the initial phase of ethics committee activity but it became clear that major issues to do with reproduction, death and dying, informed consent and access to health care were going to be a national rather than a local challenge, and therefore the idea of a national committee was gradually mooted and then accepted.

Both the national and local committees worked to a set of guidelines called the National Standard for Ethics Committees the latest revision of which was in May 1994. This covers such things as the idea of ethics committees, the scope of their interest, their accountability and monitoring arrangement, their composition and membership, and the process which

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should be gone through for matters to receive ethical review from an ethics committee. The National Standard in some form or other has been in operation since 1989, but in its new incarnation incorporates many of the lessons learnt over the five years or so, before the recent review and restructuring was carried out.

So we now have NACHDSE (National Advisory Committee on Health and Disability Service Ethics). This Committee, in conformity with the National Standard, has a mixture of lay and professional members, and a mixture of Maori and Pakeha representation. Russell Kerse, the Chairperson, is a person very active in disabled rights organisations, and the other members include; Grant Gillett, a Bioethicist and Surgeon; Andrew Gregory, a Public Affairs Manager for the New Zealand Employers Federation and a member of the New Zealand Crippled Childrens Society; Moera Douthett, a Samoan Member;

Anne Bray, active in mental health services; Rea Wikara, manager of Maori health services; Janine Abernethy, member of patient advocate services; Mereana Ratana, a Maori member of the Taranaki Ethics Committee; Elizabeth Cunningham, a Maori health advisor to the Southern Regional Health Authority; and Catherine Ryan, a lecturer in management, a solicitor, and a member of the Waikato Ethics Committee. This means that there is quite an interesting mix of experience on the Committee, with women members slightly outnumbering men, but a good balance of Maori and Pakeha and among the non-Maori, one Samoan.

This Committee will meet regularly, will supervise and monitor the operation of local ethics committees,

and will, in consultation with the Health Research Council, develop and improve the National Standard to the point where it becomes a workable and effective document for ethics review in New Zealand. It is to

be hoped that the informal national networking arrangements will continue to be in place, and that the ethics committee structure will be well fostered by the new arrangements.

The National Ethics Committee is due to meet in February for the first time and will, I am sure, on that occasion be defining its agenda for the next year or so. It is obviously an important initiative that the Government has seen fit to appoint a committee concerned with ethics to work closely with senior administrators in the Ministry of Health and with the Minister. We would hope that this means that issues of patient rights, quality care, patient safety and research, and equity and justice in health care are to receive close attention in the New Zealand health care system. It will be interesting to see how the new committee shapes up, and how it forges its relationship with the major players in the health care arena over the next few years.