

have been available for professional and public scrutiny.

Health Care Delivery

In 1991 the National Standard expanded the functions of ethics committees to include "any matter of ethics relevant to health care delivery". In 1993, following the health reforms, an interim task group was set up to advise on the transfer of ethics committees from Area Health Boards. The ethics committee chairpersons' submission concentrated on health care delivery issues and stressed the need to retain a consumer voice in the new system and the need for ethical review at multiple levels in the reformed system. The task group recommended the establishment of a National Advisory Committee on Health and Disability Services Ethics. Health care delivery issues were also retained in the revised 1996 National Standard.⁶ The national committee might have been expected to advise the Minister on the ethics of new health policy initiatives, but the Minister has not sought its advice. Practical issues in the ethics of health care delivery might also have been addressed at the regional level, but there have been difficulties, as shown by the Stent report into Canterbury Health.⁷ Moreover, some regional ethics committees have not addressed such issues at all.

Implications

Research and innovative treatment should continue to be considered together, by the same committees. But the attempt to insert ethical review at multiple levels into the reformed health system needs to be re-thought. The primary motive was probably to retain a public voice in a system devoid of input from elected representatives, but it didn't work. Arguably it shouldn't have worked, as ethics committees have no public mandate to decide national or local health policy. Right now very troubling decisions are being taken by the Health Funding Authority. A method of prioritizing health services according to a principle which would decide "equity" according to the health outcome for groups is being contemplated. This could leave health services with no obligation to provide care to all individuals on the basis of need, as has existed – at least implicitly – until now. This is a major political issue and shouldn't be decided behind closed doors by economists or even ethicists. Similarly, at a regional level, ethics committees were in no position to stop the disastrous management practices which have afflicted hospitals in Christchurch and Dunedin and elsewhere since the reforms. Elected representation on health boards is a more power-

ful way of retaining a consumer voice. Then separate committees on health care ethics operating close to local services could make an appropriate contribution.

References

- ¹ Richmond, D.E. Auckland Hospital ethical committee: the first three years. *NZ Med J* 1977; 86: 10-12.
- ² Cartwright, S.R. *The report of the cervical cancer inquiry*. Auckland: Government Printing Office, 1988, p. 152.
- ³ Department of Health. *Standard for ethical committees established to review research and treatment protocols*. Wellington: Dept of Health circular memorandum, 1988.
- ⁴ Harvey, V., Evans, B. Research and patient care: what needs review and by whom? *NZ Med J* 1989; 102: 229.
- ⁵ Department of Health. *Standard for ethics committees established to review research and ethical aspects of health care*. Wellington: Department of Health, 1991.
- ⁶ National Advisory Committee on Health and Disability Services Ethics. *National standard for ethics committees*. Wellington: Ministry of Health, 1996.
- ⁷ Health and Disability Commissioner. *Canterbury Health Ltd*. Auckland: Health and Disability Commissioner, 1998, pp. 115-8.

Interview with Barbara Nicholas

Barbara has accepted a new position with the New Zealand Technology Assessment Clearing House which is part of the Department of General Practice and Public Health at the Christchurch Clinical School. In this interview Barbara reflects on seven years with the Bioethics Centre.

OBR: What have you enjoyed most about working at the Bioethics Centre?

BN: The highlight of working in the Centre has to be the chance to work with such a diversity of people. There have been some absolutely wonderful students who have come through the Bioethics Centre, with vast life experience and lived wisdom which they bring to class and to conversations between class. I've really enjoyed working with a variety of people around the medical school and across

the university and being involved in interdisciplinary projects. And I've really enjoyed working with people around the country, on organisations such as the National Ethics Committee on Assisted Human Reproduction and the Health Research Council ethics committee, doing workshops with community groups, and being part of planning bioethics conferences. I have met so many amazing people who are involved in ethics. This is, I think, one of the very distinctive things about New Zealand ethics – we have such a breadth of people involved. Ethics hasn't become something that only the experts can contribute to, but a series of conversations where an enormous range of people can contribute to policy and practice and to the thinking through of new challenges.

For me, the exciting thing about working in bioethics is that it is so interdisciplinary. Every time I have a conversation with people they are asking different questions and looking at things in a different way, so it is almost impossible to get stuck with one interpretation. There is always the challenge of needing to think about things differently and engaging in fresh questions.

OBR: What have you done that you feel most pleased or excited about while at the Bioethics Centre?

BN: The teaching has been a highlight. I've been involved in establishing some of the new courses for both the Masters and the undergraduate programmes.

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ening and are identifiably potentially harmful in specifiable ways, such as the catheterisation of healthy children to measure their pulmonary artery pressure in order to compare it with that of children with congenital heart disease, we cannot justify the risk, useful though the information might be.⁴ The principle of *primum non nocere* will always outweigh the principle of beneficence in non-therapeutic research.⁵

In therapeutic research we can find a more acceptable definition of minimal risk. Here the risk posed by the intervention must be no greater than that posed by standard methods of treatment or by non-intervention, where the consequences of the latter would be harmful.

Thus the possibility of perinatal research is not closed, but it is, nevertheless somewhat circumscribed by the inability of the patient to provide a consent.

Therapeutic Interventions

We have already discussed the vagueness of the line between research and practice in perinatal medicine and proposed that the interests of the patient should always be decisive in any decision to engage in innovative treatments. There might be radical disagreement about what are the best interests of the patient. There is always the possibility of a conflict between the narrative of the clinician and that of the patient. The clinician might be eager to test a new hypothesis, evaluate a new technique, initiate a new practice and so on, all of which are justifiable aims in a professional career. Parents' concerns may often be called in aid of such agendas when the prospect of losing their child is apparently intolerable. However these considerations must always be weighed against the cost to the patients who should not be left to drop out of the decision procedures simply because of their dire needs or their inability to frame and voice opinions about their treatment. Hindsight is, of course, a fine thing but we can identify some procedures which, on reflection, we might feel did not take such concerns seriously enough where extraneous considerations dictated practice. Such was the case of four-year-old Laura Davies who had been refused transplantation surgery in the UK because clinicians felt that it was not in her best interests given the suffering involved and the

extremely gloomy prognosis. Her gut was not functioning and she had been kept alive by intravenous feeding until liver failure occurred. Survival depended on liver and bowel transplantation – very experimental surgery with too few historical cases to estimate reasonable chances of survival. Eventually she endured multiple transplantation of seven internal organs spending the last months of her life undergoing harrowing heroic procedures. This raised the question of whether some paediatricians felt there was no point at which to call a halt to innovative practice.⁶

This paper has argued that there are limits to both research and therapeutic intervention in perinatal medicine, difficult though they might be to determine. Ethics committees can best play a valuable role in identifying these limits where the distinction between research and practice is not used as a mechanism for evading independent ethical review. In New Zealand the remit of ethics committees makes such evasion theoretically impossible but elsewhere, such as in the United Kingdom, the review of clinical practice is not part of the brief of Local Research Ethics Committees. Nevertheless even in New Zealand the proportion of innovative procedures reaching ethics committees is very low as yet. This is a matter of concern which is currently a focus of attention.

References

- 1 For a discussion of this difficult area see Donald Evans and Martyn Evans, *A Decent Proposal: ethical review of clinical research*, John Wiley and Sons (1996), Chapter 4 'Experimental Clinical Practice', pp. 51-61.
- 2 Alderson, P. 'Did children change or the guidelines?' *Bulletin of Medical Ethics* 80 (1992), pp. 21-28.
- 3 Nicholson, R. (ed.) *Medical Research with Children*. Oxford University Press (1986), Chapter 5.
- 4 Howell, Rodney R. 'The importance of research on children', in *Research on Children*, Jan van Eys (ed.) University Park Press (1978), Baltimore, p. 35.
- 5 Jonas, H. 'Philosophical reflections on experimentation on human subjects', *Daedalus* 98 (1969), pp. 219-47.
- 6 Nicholson, R. Editorials, *Bulletin of Medical Ethics* 78 (1992) and 91 (1993).

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In the early days of the Centre there was, I think, an expectation that it would be doctors and lawyers who would come and do postgraduate study in bioethics. But we have discovered that many different people come to study ethics – some young, some older with lots of professional expertise, people from a range of health sciences, and people coming from the humanities. There have been some great challenges in designing courses that can meet the educational needs of such a range of students.

I've also enjoyed being part of the development of the new undergraduate medical curriculum. That has been fun because of working with the different people across the medical school, thinking through how we can best do this. It's been an opportunity to try out new ideas. And it has been exciting to see it come to fruition and be part of the changes to ethics education as we move into a new curriculum at Otago.

OBR: What about some of the research that you have been involved in?

BN: Some of my research has focused on ethics education: what we do, why we do it, what we are hoping to achieve both in terms of working with medical students and with graduates. I really enjoyed being part of the Feminist Pedagogy Research Group, an interdisciplinary group looking at how feminist pedagogy could inform our teaching. Again this was the stimulus of working with people across the different disciplines and the excitement of dealing with different questions.

My more recent research has been looking at the implications of the new genetics and the issues for scientists as they generate new knowledge and present society with new choices about how we are going to deal with these technologies. This is a field that is going to need continuing work.

OBR: What will you miss most about leaving the Bioethics Centre?

BN: What I am going to miss most are some of the people associated with the work of the Centre, and the excitement of students discovering new ways of thinking about things, gaining confidence in the ability to think things

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New Name

The Bioethics Research Centre has had a name change. As from the beginning of the year our name is now the Bioethics Centre. A marked increase in teaching commitments has changed the emphasis of the Centre and the change in name is designed to reflect this.

New Staff Arrivals

At the end of 1998 two new staff members were appointed to replace Dr Barbara Nicholas and Dr John McMillan, who both left during the year. Neil Pickering from Swansea in Wales will be the first to take up his appointment as Lecturer within the Centre. Neil has a broad interest in bioethics and has researched and published on many topics including: genetics, medical humanities, ethical issues in mental health, resource allocation, reproductive medicine, ethical review of research, and ethical issues in child health. We are all eagerly awaiting Neil's arrival and are looking forward to working with him.

Dr Jing-Bao Nie, originally from China but more latterly from North America, is the second appointment. Jing-Bao is qualified in Traditional Chinese Medicine, and has studied extensively in bioethics and medical humanities. Jing-Bao's interests in bioethics include: abortion in China, medical humanities, cross-cultural ethics, qualitative research, and philosophy of medicine. Jing-Bao will be a valuable addition to the staff and we extend a very warm welcome to him and his family as they move from Minnesota to New Zealand.

Lynley Anderson has also been appointed as a lecturer part-time.

Travels

In November Professor Donald Evans attended the first Emirates International Congress on Perinatology in Abu Dhabi where he presented three papers entitled: 'The limits of perinatal practice', 'Successful outcomes in perinatal medicine', and 'The status of the perinatal patient'. Professor Evans then went on to the UK where he was a Visiting Fellow at the Institute of Health Sci-

ences at Oxford University, during which time he read a paper entitled 'Medicine as a form of social control'.

Professor Grant Gillett is currently at Oxford University following a trip through India. More on his travels in the next issue.

Visitors to the Centre

Dr Martyn Evans will be visiting and working at the Centre during March and April of 1999 to help with the teaching load until the new staff come on board. Martyn was a colleague of Professor Donald Evans at Swansea University where they collaborated on a number of projects. Martyn took over position as Director when Donald moved to New Zealand.

Summer Studentships

Prior to Christmas two medical students were awarded Health Research Council summer studentships in ethics. These grants allowed Chris Jackson and Ben Campbell to work on projects in bioethics over the summer months. Chris Jackson has spent his time exploring the dimensions of the student/patient relationship particularly pertaining to informed consent and confidentiality. Prior to the completion of his project, Chris will be reviewing the policies at Otago Medical School. Meanwhile, Ben Campbell has been examining the question of inducements in health research. This study will involve an assessment of national guidelines on this topic.

Research Project for the Health Funding Authority – National Waiting Time Project

Also over the Summer months Professor Donald Evans, with the assistance of Neil Price (a fifth year medical student and Centre graduate) has been conducting research for the Health Funding Authority into the ethical issues involved in the National Waiting Time Project. The project has involved an appraisal of the arguments already in the literature and raising other ethical issues surrounding this topic. ■

through in new and fresh ways. And I'm going to miss working with some of the amazing women associated with the centre, both as staff and as students, who have the courage to work in new ways and do research into areas that have been ignored or minimised in the past.

OBR: What do you consider to be the ethical issues that will face us in the future?

BN: I think the ethical issues are going to be on two fronts. There are the high profile ethical issues of how we use new technologies, and how we deal with immediate clinical situations. For instance, how we are going to integrate our understanding and knowledge of genetics into how we offer medical care. But I think there are some more significant ethical issues that are to do with the health implications of our social and political ethics. How we are going to structure society so that everybody is able to be adequately cared for and valued, if indeed we think such things are important? And how are we going to respond to larger social forces that seek to change social practices and associated values for the sake of economic benefit; for example, the pressures of transnational companies who wish us to take on certain environmental and health risks with respect to genetically modified organisms, or the increasing involvement of private health providers in delivering basic health services? What values inform our understandings of what it means to be a community together?

Ethics is about asking critical questions, not about answers. It is about opening up issues to look at the values that are operating, and who benefits and who is silenced. If we can do this then I think we can make a major contribution to the conversations about how we can deal with rapid social change. There is a risk that society will ask people in ethics to be authority figures, to take the role that was traditionally fulfilled by institutions such as the church, to provide society with the 'right' answers to difficult questions. I think that if we buy into that as ethicists then we have not fulfilled our responsibilities, which are more about helping people to open up questions and to think through and to live through difficult situations. ■