new developments

Bioethics and Health Law in New Zealand

bioethics commentary

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As will become evident from the discussion that follows some of the 'new developments' in bioethics have been mentioned in this review article every year since its inception in 2001 while other, seemingly new issues, are simply old issues in a new guise. 2003 seems to have been characterised by debate on the importance of personal autonomy and privacy versus issues of public good as epitomised by the ongoing cervical screening debate.

National Cervical Screening Programme

Organised cervical screening was established in New Zealand in the early 1990s following the recommendations of the Cartwright Report. Although screening programmes can be effective in reducing the incidence of cervical cancer they are not without their limitations and are not able to prevent all cases of invasive cervical cancer. However, these limitations can be minimised if the programme is monitored and evaluated properly (Brady, 2003). In Gisborne the under-reporting of cervical cancer by one pathologist raised concerns that monitoring of the New Zealand cervical screening programme was inadequate. A Committee of Inquiry was set up and its report, released in April 2001, raised some serious concerns about the effectiveness of the programme and made 46 recommendations for improving the scheme. Progress in implementing the changes has been reviewed by an independent expert, Dr Euphemia McGoogan, who has also raised additional issues and recommendations. Four of these recommendations relate to improving access to medical records and screening data to allow for more effective evaluation and audit.

Currently if an evaluator wants to access data held on the cervical screening register consent has to be obtained from the woman herself. One problem with this is that some women can be difficult to trace causing unacceptable time delays. Another problem is that if too many women withhold their consent insufficient data will be generated to produce meaningful results. The committee recommended therefore that legislation should be enacted to allow auditors access to notes without consent. This would be achieved by the Health (Screening Programmes) Amendment Bill. (For a discussion on whether or not legislative change is the best way to proceed see Paul, 2001)

In September 2003 the Health Select Committee published its report on the Health (Screening Programmes) Amendment Bill. The Committee recommended that programme evaluators should have access to women's primary-care health records as well as to notes held by private specialists and public hospitals, without the need to seek express consent from the women concerned. The committee believed that this change was necessary to provide greater accountability and consequently a safer system for all women. It was also in line with recommendations made in the McGoogan Report.

For several days debate continued in the media with writers polarised by their views on privacy and confidentiality. Green

MP Sue Kedgley was concerned that evaluators would have access to other sensitive information such as sexual abuse and terminations as well as a woman's cervical cancer history and that this would be a potential threat to the special trust relationship which currently exists between medical practitioners and their patients. There was a general concern that this would result in a decrease in the number of women enrolled in the programme (*Otago Daily Times*, 2003a).

The New Zealand Medical Association also raised concerns about potential harm to the doctor/patient relationship. Their view, as expressed in the newspaper article, was that informed consent should be gained from individuals before records could be accessed. One Christchurch GP is reported as saying that 'The right of women to have full confidentiality around their medical information is not negotiable' (*Otago Daily Times*, 2003b). This view was also supported by Gillett (2003) who warned that allowing researchers direct access to records could result in women loosing confidence in the health system as well as damage to the doctor/patient relationship.

Conversely statisticians and epidemiologists claimed that women had to make a choice between complete privacy or a safe cervical screening programme and that it was not possible for them to have both (Herbison, 2003). The Bill provided assurances that evaluators who would have access to notes are all qualified health professionals and as such are subject to the same privacy and confidentiality constraints as all other health care professionals (*Otago Daily Times*, 2003c). Of course, while this may be true it is arguable that they would in fact be subject to the same constraints as they would not be in a therapeutic relationship with the women concerned and it is this relationship that gives rise to the duty of confidentiality. Conversely, others argue that it is the professional role which gives rise to the duty of confidentiality and not the therapeutic relationship itself.

Euthanasia

The issues of euthanasia and assisted suicide continue to make the headlines. In the past the debate focused on euthanasia as a way of dealing with intractable pain but now, with the improvement in pain management and the increase in access to palliative care, the emphasis seems to have shifted to issues of loss of personal dignity, psychological pain, the right of individuals to make their own choices and even loss of dignity of a loved one. For example an elderly man who suffocated his wife with a plastic bag in December 2002 did so because she had increasingly severe dementia. The man had intended to take his own life too but lost consciousness before he had achieved his aim. Although he was charged with murder he was granted a stay of prosecution because he was too ill to undergo a trial. In a letter published in the *Dominion Post* he said, 'As a human being, I should have the right to choose whether to carry on living like a vegetable or to take my own life. I would not expect anybody, not even a doctor to end my life physically, but I would expect to ask a friend or someone willing to help me ... and such a person who is willing to help should not be prosecuted as a criminal and no stigma should be attached to him' (Voluntary Euthanasia Society).

In another case, Lesley Martin, who confessed to killing her mother in her book *To Die Like a Dog*, was arrested and charged with attempted murder. In a depositions hearing in August it was found that she did have a case to answer and her trial is expected to take place in March this year. In an interesting coincidence on the same day that Lesley Martin was arrested MP Peter Brown's 'Death with Dignity' Bill was drawn from the Private members ballot box. However, it failed to cross its first hurdle in parliament in July when it was narrowly defeated in a conscience vote by 58 to 60. This reflects an interesting change in opinion from 1995 when Michael Law's 'Death with Dignity' Bill lost its first reading by 29 to 61 with many members of parliament abstaining from the vote.

These examples seem to demonstrate that both the Courts and Parliament are opposed to law changes in this area despite public concern. The increasing number of cases involving suicide pacts and the assisted suicide of elderly parents or partners suggests that this is an issues which will continue to exercise ethicists and legislators for some years to come.

Assisted Reproduction

New Zealand, like most of the world's developed countries, has long recognised the need for comprehensive legislation to regulate human reproductive practice and technology. Since 1985 a series of issues papers and reports have been published culminating in 1996 with Diane Yates' Human Assisted Reproductive Technology Bill (HART Bill) and the government's Assisted Human Reproduction Bill (AHR Bill) in 1998. The two bills were passed to the Health Select Committee and submissions were sought. However, the Committee did not finish its consideration of the submissions or report the Bills to the House. These delays may have been fortuitous as, since they were written, technology and scientific knowledge in the area of assisted human reproduction has progressed and there have also been significant developments in legislation overseas. The government's proposals were released in May 2003 by Associate Justice Minister, Lianne Dalziel, in the form of a Supplementary Order Paper (SOP) to the Human Assisted Reproductive Technology Bill.

As already mentioned by Atkins (2004) one of the issues covered by the SOP is that of anonymity of donors of gametes and the rights, if any, of donor offspring to identifying information.

In the usual course of events children are genetically and physically connected to their mother and genetically connected to their father and through them to their wider family heritage or *whakapapa*. Assisted reproductive technologies, however, allow for a break in the genetic links as sperm, eggs, the gestational womb, the social mother and the social father can all be combined in artificial ways (Else, 1999). The implications of this mixing affects all concerned – the donors as well as the resulting child. ART providers focus on the problem of 'getting a woman pregnant' and their immediate sphere of concern is the rights and desires of the adults involved with little or no consideration given to the rights of the offspring despite the fact that the repercussions last for the lifetime of the offspring and even beyond. The only link between all of the participants is the provider clinic and yet record keeping by clinics has been self-regulated and inconsistent. A step forward was made about six years ago when fertility clinics in New Zealand voluntarily agreed to only accept sperm from men who were willing to be identified once offspring reached the age of 18. However, if the child does not know the circumstances of their birth then it can be argued that this means very little. The SOP seeks to address this issue of information by requiring providers to collect certain information about donors and to keep a record of offspring births (Part 4).

New Zealand's adoption history has led to an understanding of the issues involved when a genetic break occurs in the usual parent/child relationship and it is interesting to compare this with the problems surrounding ART births. The New Zealand *Adoption Act 1955* was formulated to support the notions of ignorance, concealment and secrecy about adoption which were prevalent at the time. The rights and needs of adults were of paramount concern and there was a belief that a complete break between the child and the genetic parents was in the best interest of both parties. This attitude seems to have pervaded early ART. Writing in 1957 Bloom states 'For the child's sake particularly I prefer that absolutely nobody but the parents themselves should know of the donor insemination therapy. My last advice to the parents is that under no circumstances should they, or need they, ever tell the child the method of conception – in fact they should forget about it themselves' (in Coney, S (1999) p 27). This attitude is further borne out in the common advice given by doctors that a couple should return home after the donor insemination has taken place and have intercourse so that if conception occurs there remains the possibility that the child would actually be that of the male partner and not that of the donor, perpetuating the idea that secrecy is the best policy to adopt.

Gradually since 1955 the attitude of secrecy has undergone changes. Adult adoptees began to talk about their experience, often describing their feelings in terms of 'alienation' from their family or simply a sense of 'being different'. These individuals began to campaign for their right to know about their biological origins and to campaign for more openness in sharing of information. The campaign reached a climax in 1985 with the passing of the *Adult Information Act* which gave adults the right to access their original birth certificate. There are obvious differences between adoption and assisted birth technology but the lesson learnt from adoption about the need for adoptees to be told of the facts surrounding their birth could equally apply to the offspring in ART. However, as Nelson (2000) states current practice in ART 'sunders children from social recognition of their biological connections to a parent, in order to provide adults with socially recognised biological connections to the children they raise' (p5).

Another thing to be learnt from the adoption experience is that the need to know goes beyond knowing the donor's name, physical characteristics and medical history. Offspring want more personal information about their biological parents, a form of social connectedness to them, asking such questions as: why did they choose to donate, do I have any half siblings, what about my grandparents. There is a suggestion that one way of 'filling in the gaps' for offspring would be for there to be a meeting between donors and recipients. This could not be legislated for but it could be mandatory for providers to offer it as an option for recipients. This would go some way towards restoring the human connection in the technological process (Atkins, 2004; Coney, 1999).

The question remains as to whether or not the provisions of the Bill make access to information a reality for the offspring of ART procedures. The Bill clearly states in its opening principles that 'the health and wellbeing of children born as a result of an assisted reproductive procedure should be paramount in all decisions about that procedure' (4(a)) and that 'donor offspring should be made aware of their genetic origins and be able to access information about those origins' (4(d)). It is debatable whether, without a change in the system of birth registration, this will be achieved by the current SOP proposals. The Bill also fails to address other issues that relate to the best interests of children such as intergenerational donation, interracial donation and the use of gametes from cadavers or foetuses.

If children are to be given the right to access their birth information then that right must correspond to a duty to disclose. As Mahoney, J states 'we are in danger of repeating the mistakes around adoption with assisted reproductive technology by concentrating on the medical issues around satisfying the needs and rights of adults' (p.15). Currently the Bill gives donors the right to know that a child has been born but does not give that child the corresponding right to know that they have been born as the result of gamete donation. The Minister of Justice states quite clearly that 'the proposals do not require a donor offspring to be told about the circumstances of their conception – this decision rests with the child's family' (p.7).

If, as some would have us believe, nurture is more important than nature then children may decide that they don't want to make contact with their biological parents. However this is surely a decision for the individuals themselves. The evidence provided by ART is that adults will go to extraordinary lengths to 'have a child of their own' – one that is genetically linked to at least one of them, suggesting that biological connectedness, is significant to parents. There is no reason to believe that this interest in biological connectedness is unidirectional. There is plenty of reason to think that biological connectedness with progenitors is at least as important as links with descendents (Nelson, 2000). One way of making the system more transparent would be by issuing birth certificates which make origins explicit. The Bill as it stands does not deal with the issue of birth certificates and this is a key issue in both ART and adoption in ensuring that offspring have the prior knowledge that they need in order to exercise their information rights.

However, it is also important to bear in mind the fact that only around 150 of the 55,000 children born in New Zealand each year are born as a result of gamete donation. Further, around 1,500 children have birth certificates with no fathers name on them and estimates suggest that between 1,000 and 5,000 may have the wrong father on the birth certificate and so the position of children born as a result of ART in not being able to trace their genetic background is not as unique as may have been thought.

Committees and Councils

a) National Ethics Advisory Committee (NEAC)

NEAC has been concerned with a review of the role of ethics committees and research. The committee reported to the Minister of Health in December making recommendations in all four areas that it was asked to investigate and is now waiting for a report from the Ministry of Health.

b) Bioethics Council

In October 2001 the Government agreed to the establishment of Toi te Taiao, the Bioethics Council. The membership of the Council was announced in December 2002 and the terms of reference in January 2003. The purpose of the Council is to enhance New Zealand's understanding of the cultural, ethical and spiritual aspects of biotechnology and to ensure that the use of biotechnology has regard for New Zealanders' values. The many challenges facing the council have been outlined in a previous edition of this Journal (Brookbanks, 2003; Crosthwaite, 2003). Both writers were all too aware of the Council's need to be committed to transparency of process and also to have the ability to deal with divergent and powerfully expressed opinions.

The council is currently involved in several projects including an exploration of the cultural, ethical and spiritual dimensions of the use of human genes in other organisms, establishing Maori responses to biotechnologies, and considering the implications of human assisted reproductive technologies. A wider consultation process on the use of human genes in other organisms is due to begin in February 2004.

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law commentary

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In 2003, there were several significant staging posts in continuing sagas affecting health law. The first to be discussed touches on the delicate line between mental health law and crime. The doctor involved in the release of mental health patient, Mark Burton, who almost immediately killed his mother, was the subject of disciplinary proceedings. Secondly, Parliament passed a controversial new code regulating all the health professions. Based on the Cull Report of 2001, its effectiveness will be tested in the years to come. Thirdly, the slow progress on assisted human reproduction laws advanced with two separate legislative initiatives. With some hesitation, we may predict that an appropriate statutory framework will finally be enacted in 2004.

Mark Burton and Dr Fisher

The case of Mark Burton, who a day after his discharge from the mental health services in Invercargill killed his mother in Queenstown, received a lot of publicity. Burton was found not guilty of murder by reason of insanity. The search for someone to blame for the death switched to the medical personnel in whose care Burton had been placed.[1] Towards the end of the year, the Medical Practitioners Disciplinary Tribunal released its decision on the doctor with responsibility for Burton. It found 17 out of the 27 particulars of the charge against Dr Peter Fisher proven and held him guilty of professional misconduct. The Tribunal held that the situation did not amount to disgraceful conduct in a professional respect