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A View of Bioethics from Down Under

RACHEL A. ANKENY

When I immigrated to Australia from the United States a few years ago, at first I found many similarities between the countries. But underneath the apparent similarities, notably a shared language, lay much deeper differences in history, politics, and culture that have considerable impacts on attitudes and approaches to issues in bioethics and medicine. For instance, debates continue regarding cloning and embryonic stem cell research, particularly given the long history of research in reproductive medicine and reproductive technologies in Australia. Although there are individuals and groups opposed to such research on grounds associated with pro-life or anti-abortion stances, the discussions more often hinge on what should be funded by the government and eventually what should be provided to all within the public system of healthcare. This theme is one common thread that unites many current controversies in bioethics, but perhaps not for the reasons that an outsider might at first expect. Indeed, allocation of limited resources is part of what is considered relevant, but money is rarely presented as *the* decisive issue in these debates. Instead, considerations such as what is medically necessary (based on a broad definition of what is medical), what contributes to a “good life” (as defined by what are increasingly heterogeneous community standards), and how to respect and enable fulfillment of autonomous decisions by individuals and families in this rapidly changing context are key to many of the disputes. This brief report is necessarily selective, but it is designed to give a flavor of the terms of the debates as they are currently developing.

One ongoing debate surrounds development of regulations associated with the use and storage of human genetic samples and information—an issue that obviously has been under discussion for some time in many countries. Formal public dialogue on these matters began with an issues paper produced by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC), published in February 2001, following a joint inquiry into genetic testing and information at the request of the federal government.¹ As part of a commitment to ensure widespread public consultation, the deadline for the joint inquiry was extended until March 2003, and the paper remains open for comment.² Public consultation often is taken quite seriously during medical policy development in Australia, occurring through open town meetings in capital cities, sessions with professional and advocacy groups with particular interests in the issues under consideration, and open calls for comment from the public at large.

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At least two issues have prompted the need for clarifications in this area, beyond the obvious rapid advances in genetic technologies occurring around the world and reported cases of genetic discrimination elsewhere (though they have been relatively infrequent in Australia). First, Australia is a fairly small country—large in area, but small in population. Consequently, a large collection of Guthrie cards exists for the population, containing blood samples obtained during neonatal metabolic screening blood tests that date back 30 years. Given a nationalized healthcare system, it is theoretically possible that such information could be extremely useful for genetic and public health research if correlated with databases containing information on current health status and so on. Part of the debate over genetic privacy focuses on whether this information should be made available (with appropriate safeguards) for the purposes of public health research, and if so, should the system be an “opt out” or “opt in” one. The rhetoric sometimes has focused on the idea that Australians should be “altruistic” and that it is in everyone’s interest to contribute to furthering healthcare research, not in the least part because we all rely on the public healthcare system for much or all of our healthcare.

A second issue that has motivated the need for serious consideration of the questions surrounding genetic privacy is that some Australian researchers and biotechnology companies are going “offshore” to pursue genetic research, particularly in places with small, stable, and relatively genetically homogeneous populations with higher prevalence of certain diseases. Although these projects might be handled in a similar manner to the Iceland DeCODE project, there are clearly issues raised about “vulnerable” populations and the adequacy of community consent. For instance, there has been a debate about the use of DNA samples from the Republic of Tonga to study diabetes.³ These sorts of research projects have prompted bioethicists and community representatives, among others, to urge Australian researchers and the government not only to consider responsibilities to our own population and within our boundaries but also responsibilities beyond our shores where research is aimed at benefiting our populace.

Discussions on genetic privacy are still very much under way, and the position paper or legislative/policy measures have yet to be formalized. The bottom line so far is that there is a need to balance the potential value of genetic information for public health research with the strong need for privacy and confidentiality protection. But how the details will play out is still an open matter.

A second bioethical issue that has been in the public eye in the past few years is eligibility for access to reproductive technologies. Because of the socialized medical system, governmental funding is provided for in vitro fertilization (IVF) and other reproductive technologies. However, this policy results in considerable discussion about what selection criteria should be used when providing these technologies. Legislation exists at the state level about the details of who is eligible for services, which in turn is interpreted by administrators and providers within that state’s healthcare system. The State of Victoria had put in place legislation banning IVF services for single women (defined as those who were not married or in heterosexual “de facto” relationships, the latter of which are very common and overwhelmingly accepted in Australia) as well as self-insemination, which prompted the McBain Case (so named after the IVF practitioner who had sought a determination from the Federal Court about whether he could provide IVF to a particular single woman patient) to be

brought to the High Court of Australia. The Federal Court had ruled in 2000 that the Victorian legislation violated the Federal Sex Discrimination Act, but in response, the Australian Catholic Bishops Conference applied to the High Court for consideration, with the case being heard in September 2001. The challenge was dismissed by the High Court, which ruled that single women could not be denied access to IVF and donor insemination (DI) programs on the basis of marital status,⁴ although the ruling is generally interpreted not to apply to those who are “socially” or “psychologically” infertile⁵ and does not apply to states without specific IVF legislation.

There continue to be debates, particularly at higher political levels, about community standards for what constitutes the best interests of children (particularly whether all children have a “right” to a father and a “traditional nuclear family”) and whether these standards should be reflected in policies that allow access to IVF and DI only by heterosexual couples. For instance, this year there have been moves by the Prime Minister to amend the Federal Sex Discrimination Act to give states the freedom to restrict IVF and DI to couples. However, it is notable that public discussions have *not* been primarily focused on what should count as a “medical” condition or “clinical infertility” and whether that is a crucial factor in determining who gets access to IVF, DI, or other reproductive technologies, unlike in some other countries, although less public discussions at governmental levels have sometimes been reported to be centered on this issue.⁶ Some states are using medical necessity as a way to restrict reimbursement for such services, but because DI is currently very low cost (around AU\$100), such limits do not represent a significant access barrier, at least in some states.

A third emerging issue is the increasing amount of legal action and litigation against medical practitioners and hospitals, coupled with exponential increases in the cost of malpractice insurance in the past few years. These developments have created not just political and legal issues but have fed into ethical considerations about the conditions for provision of care, particularly within certain medical specialties or certain rural or more isolated regional areas. These problems began in Australia before September 11 but were heightened afterward, as a number of private health insurance companies (some of which are partially subsidized by the government) have had an increasingly difficult time staying in business. (Although all Australians have public health insurance called Medicare, many also take out supplemental private insurance, sometimes with employer assistance, particularly given that there are tax-based incentives to do so.) Some of the results have been that more physicians are choosing to leave private practice and there have been decreases in practitioners in particular areas of specialization that are very problematic and likely to result in reduction of availability of services. Additionally, there already have been decreases in the benefits available through private health insurance and increases in cost to the consumer. The likely outcomes are that people will choose not to continue private health insurance (which will result in increased pressures on the public system) and the availability of healthcare services will decrease in certain areas of specialization; for instance, obstetric and gynecology or certain kinds of surgery particularly at smaller health centers and in rural areas.

The final bioethical issue, and perhaps the most interesting one, goes to the core of the question of what bioethics is and what role professional societies should play in public policy. This question became particularly pressing in

August 2001 when a Norwegian ship, the *MV Tampa*, rescued 430 refugees from an Indonesian boat sinking off the coast of Australia in international waters and entered Australian waters on humanitarian grounds hoping to be allowed to have them disembark on Christmas Island, but permission was refused by the Australian government. The Australian government instead approached a number of countries in the Pacific region asking for them to take in the asylum seekers, which has become known as the “Pacific Solution.”⁷

A number of Australia and New Zealand-based bioethicists became involved because they were very troubled by the way in which these asylum seekers were treated and the way in which the media and politicians portrayed them, including accusations of throwing their children overboard as a form of political blackmail (accusations that were later found to be unsupportable at best, and at worst concocted for political purposes during an election period). There may seem to be no connection between this event and bioethics, but many bioethicists saw this as the deepest sort of bioethical dilemma, associated with fundamental human rights to life and health. The result was a statement signed by a number of Australasian bioethicists that is thought to have had considerable influence on the outcome in this case—notably, the willingness of the New Zealand government to take in some of the asylum seekers. Following several rounds of court cases and international outrage, these refugees were placed in detention centers in New Zealand, the Pacific island of Nauru, Papua New Guinea, or elsewhere offshore for processing; Australia does the processing and maintains the detention centers outside New Zealand for these refugees as well as numerous others.

The health status of these and other refugees is viewed as of deep moral concern because particularly those within Australia or in its centers are in a sense part of our population but do not have the right to care through the public health system unless they hold valid visas. Thus, they are an especially vulnerable sector of the population. Issues are continually raised about providing appropriate healthcare within the detention centers, particularly at the Woomera Detention Centre in remote Southern Australia, which has become notorious because of concerns over the mental health status of refugees, including incidents of self-mutilation and suicide as well as poor access to care, inadequate staffing, and lack of cultural sensitivity of care.⁸ Because healthcare workers at the detention centers are under gag orders, it is difficult to assess the state of affairs at the centers or for other professionals to provide support.

The refugee situation is far from resolved in Australia, given the current world political situation, with frequent new arrivals (including children without parents or family) who can be detained for up to 4 years while their claims of refugee status are assessed. As a result of these developments, there is a move in Australasia to actively reconceptualize bioethics as really being about the flourishing of human life and to look beyond the hospital and clinic to these wider, global issues as a very real part of what we need to be doing as bioethicists, including “engaging with the political.”⁹

Notes

1. Australian Law Reform Commission and Australian Health Ethics Committee. Issues paper 26 on protection of human genetic information. 2001 Oct. Available at: <http://www.austlii.edu.au/au/other/alrc/publications/issues/26/>.

2. For comments on the paper, see, e.g.: Australian Academy of Science. Comments. 2002 Jan 31. Available at: <http://www.science.org.au/academy/media/ahec.htm>; Ankeny RA. The power of privacy. *The Drawing Board: An Australian Review of Public Affairs* 2002 Jul 29. Available at: <http://www.drawingboard.info>.
3. Barkham P. Faraway Tonga cashes in on its gene pool secrets. *The Guardian Unlimited* 2000 Nov 23. Available at: <http://www.guardian.co.uk/genes/article/0,2763,401523,00.html>; Radio Australia. Tonga DNA project not going ahead. 2002 Feb 25. Available at: http://abc.net.au/ra/pacbeat/focus/PacBeatFocus_490023.htm.
4. For the judgment, see: http://www.austlii.edu.au/au/cases/cth/high_ct/2002/16.html.
5. Farrant D, Douez S. Threat to thwart IVF ruling. *The Age (Canberra)* 2002 Apr 19. Available at: <http://www.theage.com.au/articles/2002/04/18/1019020683702.html>.
6. Evans R. Victorian ALP distorts fertility debate. *Green Left Weekly* 2000 Aug 16;416:4. Available at: <http://www.greenleft.org.au/back/2000/416/416p4.htm>.
7. For details, see, e.g.: ABC Radio Australia. Australia: turning to the Pacific. 2002 Feb 25. Available at: http://abcasiapacific.com/journeys/case_australia.htm.
8. For instance, see Amnesty International Australia's fact sheet at: <http://www.amnesty.org.au/refugees/ref-fact08.html>.
9. See the ABA statement in the January 2002 newsletter at: <http://www.australasian-bioethics.org.au/>.