HUMAN RIGHTS AND BIOMEDICINE by George P Smith, II, The Hague, Klewer Law International, 2000, 229pp, ISBN 90–411–1447–5

George P Smith II has been professor of law at The Catholic University of America for twenty-five years. He is well known in Australia and Britain, as well as in North America, for his scholarship into the challenges law faces in responding to science and biotechnology.[1] Justice Michael Kirby has described him as combining 'the highest of scholarly rigour with deliberate intellectual provocation'.[2] A central theme of Professor Smith's scholarship is that law should neither shrink from the unknown landscape that science leads us into, not limp so far in the rear of science that it is unable to influence and contribute to emerging debates. Like Galileo (who was only pardoned by the Vatican on 31 October 1992, for his Copernican transgressions), Smith advocates a culture of scientific research and free discussion, reminding us that 'ignorance, not knowledge assures misery; and that the employment of science for inhumane reasons, not science in and of itself, threatens global survival' (p31). The role of law, argues Smith, is to inform itself, and from best available knowledge, to seek to maximise social good, while minimising human suffering.

Balancing the *economic* costs and benefits of the law's responses to biomedical challenges is undoubtedly a major focus for Professor Smith. At the same time, commentators have pointed out that the values of love and compassion play a central role.[3] Smith writes:

> Since the binding force of life is love, then it can be argued that men should endeavour to maximise a response to love in whatever life situations man finds himself [sic]. If an act renders more harm than good to the individual concerned, and to those around him, the act would properly be viewed as unloving. The crucial point of understanding is that a basic cost/benefit analysis is almost always undertaken – consciously or unconsciously. Of course, the methodology utilized in this assessment will be situational and incapable of absolute determination. Of necessity, the basic norm or standard to be used will be love (pp91–92).

A 'costs versus benefits' analysis, tempered by compassion, might sound benign. The devil, however, is in the detail, and how one identifies and weighs relevant costs and benefits is all-important. Libertarians are likely to react against the emphasis upon public benefit, rather than individual liberties, in the book. In a recurrent theme, Smith emphasises the social costs of unrestricted reproductive

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[1] See also George P Smith, 'Setting Limits: Medical Technology and The Law' (2001) 23 *Sydney Law* Review 283.

[2] The Honourable Justice Michael Kirby AC CMG, 'The New Biology and International Sharing – Lessons From the Life and Work of George P Smith, II' (2000) 7 *Indiana Journal of Global Legal Studies* 425 at 426.

[3] The Honourable Justice Kirby above n2 at 432–434; Raymond C O'Brien, "The World of Law, Science, and Medicine According to George P Smith, II" (1992) 8 *Journal of Contemporary Health Law and Policy* 163 at 166–167.

freedom and argues that '[t]he right to procreate may not include a right to breed without restrictions' (p118). Moral conservatives, for their part, are likely to question Professor Smith's upbeat assessment of the diagnostic and research technologies of biomedicine. Professor Smith sharply distinguishes himself from those commentators for whom 'bioethics' equates with earnest caution, a tendency towards prohibition, and deep pessimism about the capacity for science ever to help make the world a better place. He challenges readers:

> Genetic experimentation and planning, in conjunction with eugenic programming, are more rational and humane than alternatives to population regulation through death, famine and war or an abdication of genetic autonomy to the countervailing doctrines of gene sovereignty and biological determinism' (p53).

In Chapter 2, Smith considers scientific freedom and the role of law in regulating foetal experimentation. Countering the dystopian visions of genetic disasters and cataclysms, he argues that experimentation in human embryology and reproductive biology advances the goal of minimising suffering by reducing inherited genetic disabilities (p53). Smith equates the 'social good' that is the goal of such research with a policy that 'lessens the financial burden on citizens to support and maintain genetically defective citizens' (p27). Genetically healthy individuals, in turn, have a better opportunity 'for pursuing and achieving the "good life" and making a significant contribution to society's greater well being' (p35).

Clearing a legal space for genetic engineering, however, is another matter. Smith notes the contrast between the restrictive regulation of federally funded IVF research in America, and the lack of regulation of privately funded research (pp32–33). This disjunction is mirrored in Australia, where legislation exists in three States, with NHMRC guidelines applying elsewhere to Commonwealth-funded research, but otherwise having only ethical force.[4] In a series of well-known decisions, the United States Supreme Court recognised a right of privacy extending to marriage, procreation and contraception as an aspect of 'liberty' in the Due Process Clause of the Fourteenth Amendment (p41, 48).[5] However, whether the right to privacy extends to receiving IVF treatment is untested (and unlikely). While Britain permits limited research on embryos (pp46–47), Smith believes that no consensus on the question is likely in Congress, leading to a variety of restrictive State laws (p49). Drawing on Justice Stevens' judgment in *Webster v Reproductive Health Services*,[6] he argues that while extracorporeal embryos

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[4] See generally, Belinda Bennett, 'The Human Embryo as Property? Cryopreservation and the Challenges for Law' (2000) 7 *Journal of Law and Medicine* 434; Roger Magnusson, 'Proprietary Rights in Human Tissue' in Norman Palmer & Ewan McKendrick (eds), *Interests in Goods* (2nd ed, 1998) 25 at 55–61.

[5] See *Griswold v Connecticut* 381 US 479 (1965); *Eisenstadt v Baird* 405 US 438 (1972); *Roe v Wade* 410 US 113 (1973); *Carey v Population Services International* 431 US 678 (1977) at 685; *Planned Parenthood v Casey*, 120 L Ed 2d 674 (1992) at 698. The Due Process Clause provides that no State shall 'deprive any person of life, liberty or property, without due process of law'.

[6] 109 S. Ct. 3040 (1989) at 3083.

deserve respect as a 'symbol of life', they should not be granted the moral status of 'persons' until they are transferred to a uterus (p51). This view benefits society by helping to circumvent infertility, and to reduce the risk of genetic diseases (eg Downs syndrome). It also provides a source of embryos for infertility, genetic and cancer research, as well as a source of embryonic tissue and foetal cells (see p38). Professor Smith is likely to be disappointed by the recent guidelines from President George Bush which restrict federal funding to embryonic stem cell research using *existing* cell lines.[7] In Australia, a recent Federal parliamentary inquiry recommended a national licensing body to regulate 'therapeutic cloning' (embryonic stem cell research), but also recommended a three year moratorium on the practice.[8]

If IVF and other reproductive technologies carry the promise of healthier (happier) babies, with follow-on economic benefits for society generally, how far would Smith go to make these benefits mandatory? Given the infancy of genetic therapies, most defective genes cannot yet be cured. Harm minimisation therefore requires a 'negative eugenics' program that will reduce the number of newborns with genetic defects (p113). In Chapter 5, Professor Smith advocates mandatory premarital genetic screening, arguing that the benefits to society justify the infringement of civil liberties. The assumption is that through counselling, abortion and genetic engineering technologies, parents will choose to minimise the burden of disease upon future generations. Quoting the Episcopalian theologian and ethicist Joseph Fletcher, Professor Smith underscores the moral imperative for genetic screening: 'To go right ahead with coital reproduction in many couples' cases is like walking down a line of children blindfolded and maiming every fourth child' (p153).

Smith clearly expects individuals to make 'responsible' reproductive choices in the light of genetic knowledge, their own economic capacities, and societal interests. 'Responsible' parenthood is an underlying, yet crucial, theme in the book. It emerges in Chapter 3, where Professor Smith tackles the problem of fetal abuse and 'crack babies', criticising the view that parents should be immune from civil suits and criminal penalties.[9] In Chapter 5, Professor Smith goes on to support the right of Arizona and Nebraska to prohibit increases in welfare payments for women who have additional babies while on public assistance, noting that New Jersey, Wisconsin and Georgia have even made continued receipt of benefits conditional upon use of a contraceptive, NORPLANT (see pp129–130 & 77–79). Noting that the children of intellectually handicapped parents may themselves

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[7] George W Bush, 'Looking For a Firm Footing on an Ethical Slippery Slope' *Sydney Morning Herald* (13 August 2001); 'Bush Takes Baby Step on Stem Cell Research' *Sydney Morning Herald* (11–12 August 2001).

[8] 'Inquiry Backs Stem Cell Research' *Sydney Morning Herald* (21 September 2001); http://www.aph.gov.au/house/committee/laca/humancloning/inqinf.htm

[9] Smith asks, 'If a child may seek recovery for injuries inflicted upon it by a third person as a fetus because such injuries interfere with its "legal right to begin life with a sound mind and body", why should a fetus be prohibited from recovering against its mother for negligently inflicted prenatal injuries?' (p72). Compare, in the Australian context, *Lynch v Lynch* (1991) 25 NSWLR 411 at 425.

become 'grid-locked into mediocrity', he explores whether mentally retarded individuals should be limited in their procreative freedoms' (p121).[10] Smith doubts the value of courts (and judicial guidelines) as a procedural safeguard, citing one American case where it took a mother seven years to secure authority to sterilise her twenty-four year old mute daughter who had a mental age of 3–5 years, an IQ of 30–50 and who neither understood her sexual and reproductive functions, nor the difference between a man and a woman (pp123–4). Instead of blanket prohibitions either for or against sterilisation, Smith argues that parents should be the primary decision-makers, taking social circumstances and economic factors into account on a case by case basis (p131).

If Professor Smith does not shy from sterilisation ('negative eugenics'), nor does he baulk from the 'positive eugenics' of genetic engineering. Ever conscious of the social and economic costs of 'letting nature decide', he speculates that '[i]f the rate of pollution of the human gene pool continues to increase through uncontrolled sexual reproduction', an argument might be made in favour of cloning, as a way of compensating for the number of people afflicted with genetic diseases (p127). He points out that 30% of all hospitalised children in the United States have genetic diseases and that 6% of the population has some genetic abnormality, leading to 'twenty-nine million future years lost, or several times as much as from heart disease, cancer, and stroke' (p120). He admits, however, that legislation permitting only those with 'superior genetic traits' to clone may well fail on an equal protection challenge,[11] and that science may well be unable to 'provide a rational basis for classification of individuals based on genetic traits' (p128). Professor Smith's concern with the future deterioration of the gene pool stands in curious contrast to other commentators, whose 'slippery slope' rhetoric attaches not to the consequences of doing nothing, but of trying to genetically enhance future generations. Smith is refreshingly free, however, of the 'heuristics of fear' (p148) that characterises many discussions of cloning, and he would presumably agree with a policy that viewed cloning, like IVF, as a fertility issue. However, in Australia (as in some American States),[12] the 'cloning of a whole human being' is prohibited by statute.[13]

Given Professor Smith's emphasis upon genetic health, and upon minimising the economic burdens that ill-health place upon society, what is his attitude towards the genetic inevitability of aging and death? In Chapter 4, discussing gravely disabled neonates, he admits that while a person's life is of 'incalculable worth', there are situations where 'continued physical existence offers no benefits' (p92). Life is not an end in itself, but is valuable because it provides the context for the development of human relationships (p91). Smith devotes considerable

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[10] Compare, in the Australian context, *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218.

[11] The Equal Protection Clause within the Fourteenth Amendment provides, relevantly, that no State shall 'deny to any person within its jurisdiction the equal protection of the laws'.

[12] See, further, Ron Chester, 'Cloning for Human Reproduction: One American perspective' (2001) 23 *Sydney Law Review* 319 at 335–336.

[13] *Gene Technology Act* 2000 (Cth) s192B.

attention to 'standards of salvageability' and 'indicators of quality living', and he supports the principle of triage in the paediatric context (p102). He returns to this theme in Chapter 7, recognising that physicians are increasingly 'gatekeepers' in an environment of resource constraints, and that the focus of health care should be a reasonable level of public health rather than the 'special, cumulative needs of an individual' (p176). More controversially, he notes that the extent to which a person has cared for their own health should be relevant to the basic level of health care they are entitled to receive.

Unlike commentators such as Callahan,[14] Smith does not advocate age-based rationing determined on a 'natural lifespan' view. He argues that this would be contrary to the 'egalitarian nature of society and the principle that all human life is sacred and equally deserving of protection' (p182). Instead, and somewhat vaguely, Smith puts his faith in the capacity of the medical profession to make the necessary resource allocation decisions, assessing each patient's clinical circumstances and arriving at workable standards for deciding when further treatment is appropriate, assisted by health outcomes research (pp100, 184–185).

The theme that life is a means to an end, rather than an end in itself, suffuses the final chapter, where Professor Smith confronts the need for a working definition of 'medical futility' in end-of-life care. Adopting a well-known proposal by Schneiderman and Jecker,[15] he argues that life-prolonging treatment should not only be regarded as futile when its record of success falls below a minimum threshold ('quantitative futility'), but also where treatment 'merely preserves permanent unconsciousness or ... fails to end total dependence on intensive medical care' ('qualitative futility') (p200). Similar values underlie the discussion of pain. 'Not everyone', Smith points out, 'finds a "salvific meaning" in suffering' (p204). Noting that up to 40% of dying patients in the United States die in pain, he advocates the greater use of sedation to induce coma in those suffering terminal, incurable and irreversible conditions. For moral, political and legal reasons, Professor Smith is keen to distinguish the practice of 'terminal sedation' from physician-assisted suicide. Nevertheless, terminal sedation has been called 'slow euthanasia', particularly where comatose patients do not receive hydration and subsequently die of renal failure.[16]

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[14] Daniel Callahan, 'Aging, Death and Population Health' (1999) 282 *Journal of the American Medical Association* 2077; Daniel Callahan, 'On Turning 70: Will I Practice What I Preach?' (2000) 127(15) *Commonweal* 10; Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* (1995).

[15] For a review of attempts to define 'futility', including the work of Schneiderman and colleagues, see Paul R Helft, Mark Siegler and John Lantos, 'The Rise and Fall of the Futility Movement' (2000) 343 *New England Journal of Medicine* 293.

[16] J Andrew Billings and Susan D Block, 'Slow Euthanasia' (1996) 12 *Journal of Palliative Care* 21. Indeed, Melbourne-based euthanasia advocate Rodney Syme has argued that terminal sedation is a practice marked by 'futility, inefficiency, hypocrisy, and dishonesty': Rodney Syme, 'Right to Die Row Returns' *The Age* (2 November 1998) at 1; see also, Rodney Syme, 'Pharmacological Oblivion Contributes to and Hastens Patients' Deaths' (1999) 18 *Monash Bioethics Review* 40.

Human Rights and Biomedicine is a provocative book that covers substantial ground. In Chapter 1, Professor Smith wonders whether 'contemporary norms for global bioethical decision making are beginning to take shape and be recognized under the very dynamic concept of transnational human rights' (pp13–14). If transnational norms that engage specifically (rather than vaguely) with the challenges of biomedicine do emerge, they are unlikely to reflect any real, underlying consensus within societies themselves. Agreement over these issues may be too much to hope for. Nevertheless, Professor Smith brings home the point that the challenges of biomedicine are truly global, and cannot be ignored. His book is an impressive contribution to this transnational debate.

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