Constructions of Health

Inaugural Conference of the Centre for Health Governance, Law and Ethics
Faculty of Law, University of Sydney

Friday 4 November 2005
9.00-5.00pm

The Bar Association Common Room
Lower Ground, Selborne Chambers
174 Phillip Street, Sydney
Program

9.00am  Welcome

9.30-10.30  Globalisation and Health
Chair: Professor Don Rothwell
Challis Professor in International Law, Faculty of Law, University of Sydney
Director, Sydney Centre for International and Global Law

Globalising Rights? Constructing Health Rights in a Shrinking World
Belinda Bennett, Faculty of Law, University of Sydney

Global Health and the Normative Architecture of Corporate Economics
Thomas Faunce, Faculty of Law and Faculty of Medicine, ANU

10.30-11.00  Morning Tea

11.00-12.30  Individuals and Health
Chair: Dr Kristen Savell
Faculty of Law, University of Sydney

The Impact of the Concept of “Healthy Embryos” on Legal Constructions of Health
Roxanne Myktiuk, Osgoode Hall Law School, York University, Canada and
Jeff Nisker, Schulich School of Medicine, University of Western Ontario, Canada

Constructing a Healthy Population: What are the Responsibilities of Individuals?
Wendy Rogers, Department of Medical Education, Flinders University

Constructing the Healthy Body: From Rhinoplasty to Voluntary Limb Amputation
Isabel Karpin, Faculty of Law, University of Sydney

12.30-1.30  Lunch

1.30-3.00  Emerging Issues in Health Research
Chair: Professor Colin Thomson
Professorial Fellow, Faculty of Law, University of Wollongong
Consultant in Health Ethics, National Health and Medical Research Council

Birth, Ritalin, Prozac, Viagra, Death
David Healy, Department of Psychological Medicine, Cardiff University, UK

Research, Health and Public Trust
Don Chalmers and Margaret Otlowski, Centre for Law and Genetics, University of Tasmania

Research as Therapy: Blurring Distinctions in the Quest for a Cure
George Tomossy, Faculty of Law, University of Sydney
3.00-3.30  Afternoon Tea

3.30-5.00  **Constructions of Disability and Illness**

Chair:  Associate Professor Roger Magnusson  
Faculty of Law, University of Sydney

**Constructing “Control” Over Anorexia Nervosa**  
Terry Carney, Faculty of Law, University of Sydney

**Social Well-Being for All: Disentangling Disability and Health**  
Lee Ann Basser, Faculty of Law, La Trobe University

**If Only Killing Me Softly Were All There Were To It: Law and the Construction of End of Life Interventions**  
Derek Morgan, Faculty of Law, Cardiff University, UK

5.00  Conference Close

We gratefully acknowledge the support of the following sponsors:

Australasian Chapter of the International Academy of Law and Mental Health  
Australian and New Zealand Association of Psychiatry, Psychology and Law  
NSW Bar Association
‘Globalising Rights? Constructing Health Rights in a Shrinking World’

Belinda Bennett, Faculty of Law, University of Sydney

As the processes of globalisation reshape the economic, cultural and legal contours of contemporary society the division between local and global issues and priorities becomes more blurred. It is against this backdrop that health and health rights are also being redefined and increasingly individualised. This reconceptualisation of health and health rights has significant implications for the setting of regulatory agendas at the national and international levels. This paper explores changing conceptualisations of rights within health law, the interface between national and international regulatory responses to new developments in medical science, and the link between health and human rights.

Belinda Bennett is an Associate Professor in the Faculty of Law, University of Sydney specialising in health law. She is Pro-Dean (Teaching Programs) in the Faculty and Director of the Faculty’s Centre for Health Governance, Law and Ethics. Belinda was the founding co-ordinator of the Faculty’s Health Law Program, and is a former Associate Dean (Postgraduate Coursework) (2000-01), and former Director of Teaching Development (1995) in the Faculty. Belinda is a Board Member of the Australian and New Zealand Institute of Health, Law and Ethics (ANZIHLE). Her research explores legal responses to new technologies in health care. She is the co-editor with George Tomossy of Globalization and Health: Challenges for Health Law and Bioethics (Springer, forthcoming) and editor of Health, Rights and Globalisation (Ashgate, forthcoming) and Abortion (Ashgate, 2004). She is currently working with Don Rothwell on a project on “Globalisation and Biomedicine: The Harmonisation of Local and Global Regulatory Demands” which is funded by the Australian Research Council.

‘Global Health and the Normative Architecture of Corporate Economics’

Thomas Faunce, Faculty of Law and Faculty of Medicine, ANU

This paper initially explores the jurisprudential intersections between traditional norms that have constructed the values, aims, objectives of global health service and delivery: the moral values of health professionals, bioethics, health law and international human rights. It then compares these for legitimacy and effectiveness with principles concerning health emerging strategically from what is here referred to as “corporate economics.” In analysing whether these principles can truly be described as legitimate norms in the accepted jurisprudential sense, it attempts to set out the influence, in terms of constructing a viable regulatory concept of “health,” of what may be described as economics-at-the-service of a global corporate agenda.

Tom Faunce is Director of the Centre for Governance of Knowledge and Development's “Globalisation and Health” Project at the Regulatory Institutions Network, Australian National University. He is the Project Director of a three year Australian Research Council Project on the Impact of International Trade Agreements on Access to Medicines in Australia. Dr Faunce holds a joint appointment in the Law Faculty and Medical School at the ANU.
‘The Impact of the Concept of “Healthy Embryos” on Legal Constructions of Health’

Roxanne Mykitiuk, Osgoode Hall Law School, York University, Canada and
Jeff Nisker, Schulich School of Medicine, University of Western Ontario, Canada

The recent increase in research funding directed toward determinants of a “healthy” embryo has been stimulated in part by the desire to increase the implantation rate of in vitro fertilization (IVF) embryos, to permit higher IVF pregnancy rates and to avoid the ‘harms’ common to children born of the high order multiple pregnancies that are caused by implanting multiple embryos. Indeed, some of the funding for the research that will contribute to this paper is part of the ethics/legal component of an $850,000 Canadian Institutes of Health Research (CIHR) grant, investigating characteristics of sperm, oocytes, embryos, and endometrium, which will promote the implantation of “healthy” embryos. At the same time, we have witnessed increased research in, and clinical use of, technologies to determine the physical characteristics of the embryo (and the fetus), including preimplantation genetic diagnosis (PGD), chemical and biophysical testing, and 3-dimensional ultrasound. Embryos created in the IVF process can be screened or tested for specific conditions and, commonly, those considered “unhealthy” or “disabled” are not used for reproduction.

This paper investigates the meaning of the concepts “healthy” and “disability” when used in conjunction with embryos. What constitutes health and disability in relation to an embryo, and what are the possible implications of these concepts for our understanding and perceptions of human health status? The paper will include an analysis of the legal construction of health and disability in relation to embryos to the extent that such data is available.

Roxanne Mykitiuk is an Associate Professor of Law at Osgoode Hall Law School, York University, where she teaches in the areas of Bioethics, Health Law, Law and Disability and Family Law. She is the author or co-author of numerous articles and book chapters investigating legal, ethical and social implications of new reproductive technologies and the new genetics and the legal construction and regulation of embodiment and disability. She is also the co-editor with Martha Fineman of *The Public Nature of Private Violence* (Routledge, 1994) and the co-editor with Margrit Shildrick of *Ethics of the Body: Rethinking the Conventions* (MIT Press, 2005). From 1990-92 she was Senior Legal Researcher for the Royal Commission on New Reproductive Technologies. In 2001 Professor Mykitiuk was a member of the Provincial Advisory Committee on Predictive Genetic Testing (Ontario) and the co-chair of the sub-committee on legal and ethical issues. In 2002 she was appointed to the Ontario Advisory Committee on Genetics. She is also a member of the Ethics Committee of the Society of Obstetricians and Gynaecologists of Canada. Roxanne holds a number of research grants funded by SSHRC, the Law Commission of Canada, Health Canada, and Genome Canada. Her current work is related to legal constructions of normalcy, health, disease and illness, as well as citizen engagement in public policy and law making with respect to biotechnology.

Jeff Nisker is a Professor of Obstetrics-Gynaecology and Oncology and Coordinator of Medical Ethics and Humanities in the Schulich School of Medicine, University of Western Ontario. His national positions have included: co-chair Health Canada’s Advisory Committee on Reproductive and Genetic Technology, Executive Canadian Bioethics Society, Editor-in-Chief *Journal of Obstetrics and Gynaecology Canada*, National Council of Ethics in Human Research, Royal College of Physicians and Surgeons’ Ethics and Equity Committee and Health and Public Policy Committee, Chair Canadian Medical Association Council of Affiliate Societies. Jeff received his undergraduate and medical education at the University of Toronto, his training in obstetrics and gynaecology at UWO, and his PhD in ethics at the University of Toronto. He was awarded a Medical Research Council of
Canada Fellowship in hormones and cancer and pursued post-doctoral training at UWO, University of California, and McMaster University. Jeff holds several Canadian Institutes of Health Research and other national grants. Jeff has written many scientific articles and book chapters as well as six plays and many short stories to surface issues of ethics and professionalism and encourage compassion in health care. His research interests include public engagement in health policy development, narrative ethics, and ethical issues in genetics and reproductive medicine. Jeff has received several national and local educator awards and the Society of Obstetricians and Gynaecology of Canada President’s Award for the most significant contribution to the specialty.

‘Constructing a Healthy Population: What are the Responsibilities of Individuals?’
Wendy Rogers, Department of Medical Education, Flinders University

Health promotion and preventive health care measures such as screening and immunisation are vital parts of any comprehensive health care system. The fundamental message is that prevention is better than cure, and that we all have a responsibility to look after our own health and to keep our own bodies in good order. In this paper, I explore some of the tensions that lie behind this message, engaging with questions about the interests served by health promotion and the sometimes unrecognised balance between individual choice and state-based beneficence. Screening technologies can be tools to improve people’s health, but they can also be burdensome and intrusive and some offer only marginal health gains.

Addressing this question involves investigating what kinds of responsibilities citizens might have to be healthy and how these might be morally justified. If there are duties to be healthy members of the population, what role does government play in supporting these duties? Health promotion campaigns can be caught in a dilemma, on the one hand wishing to present information and promote individual choice, and on the other hand, aiming to produce a specific health-related behaviour such as uptake of screening. This tension between respecting autonomy and beneficence plays out in interesting ways when we also consider the pressures of commercial advertising for unhealthy products and lifestyles, and whether or not citizens have a right to be free from such pressures.

Wendy Rogers is Associate Professor of medical ethics and health law at Flinders University, Adelaide, Australia. Her main research interests include feminist health care ethics, conflicts of interest, and public health and primary care ethics. She has published numerous articles and book chapters, including work that examines the construction of menopause as a disease, the role of gender in the development and application of evidence about medical interventions, and feminist public health ethics. Rogers’ research is published in a variety of medical and bioethics journals, and she has recently published (with co-author Annette Braunack-Mayer) Practical Ethics for General Practice (OUP, 2004). She is a member of the advisory board of the International Network on Feminist Approaches to Bioethics (FAB), and a member of the Australian Health Ethics Committee, the Gene Technology Ethics Committee and the Medical Board of South Australia.

‘Constructing the Healthy Body: From Rhinoplasty to Voluntary Limb Amputation’
Isabel Karpin, Faculty of Law, University of Sydney

This paper contrasts the legal and ethical responses to body modification practices. First it explores our legal and ethical response to cosmetic surgery that has the goal of aesthetic normalisation or an improved aesthetic outcome. Second it examines legal and ethical responses to apparently disabling surgeries. Here I explore the desire to have so-called “healthy” limbs amputated. Third I examine legal and ethical responses to transgender surgery.
I examine all three of these body modification practices through a lens that explores concepts of normalcy, health, disability and embodiment. I take as my starting point Annemarie Bridy’s radical suggestion that the impulse to have a healthy limb removed can be seen as “implicitly challenging the pervasive stigma of disability not only by embracing but by seeking to literally embody an alternative conception of bodily integrity.” I interrogate this notion of bodily integrity and compare its medical, legal and social conceptualisation to provide guidance as to regulatory responses.

Isabel Karpin is a Senior Lecturer in the Faculty of Law at the University of Sydney, specialising in feminist legal theory, health law, law and culture, and constitutional law. Her research has been concerned with rethinking legal and medical approaches to the body, as well as legal responses to developments in genetic technologies and the challenges posed by these new technologies to legal understandings of individuality, identity, and family. One of her most significant contributions to this area has been her conceptualisation of the pregnant women as not-one-but-not-two adopted by the Australian Medical Association in its major 1995 *Fetal Welfare and the Law Report*. Recent publications include ‘Genetics and the Legal Conception of Self’ in Roxanne Mykitiuk and Margrit Shildrick (eds), *Ethics of the Body: Postconventional Challenges*, (MIT Press, 2005) and ‘Speaking into a Silence: The Australian Constitution and the Rights of Women’ with K O’Connell in Beverly Baines and Ruth Rubio (eds) *Constituting Women around the World* (Cambridge University Press, 2005).

**Emerging Issues in Health Research**

*Chair: Professor Colin Thomson*

*Professorial Fellow, Faculty of Law, University of Wollongong*

*Consultant in Health Ethics National Health and Medical Research Council*

**‘Birth, Ritalin, Prozac, Viagra, Death’**

**David Healy**, Department of Psychological Medicine, Cardiff University, UK

In recent years the marketing power of pharmaceutical companies has become increasingly apparent to perhaps everyone except physicians. Physicians see and decry the gimmickry of sales departments – free meals, conflict of interest issues and visits from company representatives. They typically fail to recognise that the goal of marketing departments is to create the consumer, to whom sales sell the product - in this case the physician as consumer, who is being educated to see an ever broadening set of risk factors as diseases in need of urgent intervention.

Ultimately the goal of marketing which involves the creation of consensus would appear to conflict with the goal of science, which supposedly progresses by disturbing consensus. The recent controversies in the treatment of childhood depression, in which it appears the entire “scientific” literature may have been ghostwritten and can now be seen to stand almost completely at odds with the raw data it purports to represent provides a point of crisis in biomedical science and a rare opportunity for research in the sociology of science. The marketing power involved here has clear implications for any efforts to pursue the history or sociology of healthcare, the interface of law and health, and for public health in general.

David Healy studied in University College Dublin and University of Cambridge. He is a Professor in Psychological Medicine in Cardiff University, a former Secretary of the British Association for Psychopharmacology, and author of over 130 peer reviewed articles and 15 books, including *The Antidepressant Era*, and *The Creation of Psychopharmacology* from Harvard University Press, *The Psychopharmacologists* Volumes 1-3, and Let Them Eat Prozac from New York University Press. Healy is also a Visiting Professor at the University of Toronto. He has been a consultant to most major pharmaceutical companies but also an expert witness for plaintiffs in cases against pharmaceutical companies.
This paper explores the relationship between research and health and the significance of “public trust” in maximising the health potential of research. Medical and scientific research over past decades has played a vital role in improving the health of the population. More recently, developments in relation to the Human Genome Project hold great promise for advancing our understanding of genetically based disease. In the post-genome era, research is aimed at the prevention, diagnosis and personalised treatment of illness, and promotion of public health. Much interest is now also turning to large scale population genetic databanks as a key resource for promoting health research, with a number of such databanks being established around the world, including the UK Biobank. The success of the research effort depends to a great extent on the altruism of patients and members of the public to volunteer their participation in research, through undergoing testing, trialing drugs and providing samples.

Since Nuremburg, protection of the subject has been the key focus in the ethics and regulation of medical research. Whilst acknowledging the centrality of the individual research subject, this paper seeks to highlight a broader, public interest perspective which demands the attention of regulators and policy-makers; ensuring that the public can have confidence in the research undertaken and that individuals are not deterred from participation though concerns about breach of privacy or other misuse of information and/or samples that they have provided. This paper argues that ensuring public trust is particularly important in the sensitive area of genetics, to both facilitate research participation and also maximise the uptake amongst the public of the medical advances that that research yields.

Don Chalmers is Dean and Head of the School of Law at the University of Tasmania and Director of the Centre for Law and Genetics at the University of Tasmania. He is Chair of the Commonwealth of Australia Gene Technology Ethics Committee, established under the Gene Technology Act, Deputy Chair of the Embryo Research Licensing Committee and Chair of the Australian and New Zealand Institute of Health Law and Ethics (ANZIHEL). His former appointments include Chair of the Australian Health Ethics Committee (1994-2000), member of the National Health and Medical Research Council Executive (1994-2000), Chair of the Tasmania Enquiry into Artificial Conception (1985-86), Chair of the Commonwealth Ministerial Review of the National Ethics Committee system (1995), and Law Reform Commissioner in Tasmania (1991-97).

Margaret Otlowski is Professor at the Faculty of Law, University of Tasmania and Deputy Director of the Centre for Law and Genetics. Margaret has longstanding experience in health law and bioethics, having published extensively in the field, worked as consultant for Commonwealth and State bodies including the former National Bioethics Consultative Committee and the Australian Law Reform Commission (in connection with its inquiry in the protection of human genetic information), and served on various Committees and Tribunals including the Tasmanian Anti-Discrimination Tribunal and Chair of the University of Tasmania Human Research Ethics Committee and for the new Tasmanian statewide committee.

The distinction between “research” and “therapy” has always been hazy, operating along a continuum of certainty (or uncertainty) about the expectation of therapeutic benefit. While even the value of “established” therapies may be subject to disagreement within the healing professions, the lack of definitional clarity (and often the corresponding level of controversy) is greatly enhanced in early phase clinical trials and in cases involving “innovative therapies.”
It is not surprising, therefore, that the “therapeutic misconception,” first coined by Paul Appelbaum in 1982 to describe the confusion by some patients about the therapeutic benefit of a research intervention, has remained an important topic in research ethics discourse. Social forces continue to propagate such misunderstandings and the responsibility for its prevention cannot be laid solely at the feet of physician-investigators. With the proliferation of clinical trials and associated market pressures to recruit human subjects, coupled with the quest by patients and consumer advocates for cures that has been fueled by heightened public awareness and global access to innovative treatment alternatives, the “therapeutic misconception” has moved beyond an ethical quandary to become a societal dilemma.

This paper advocates against the increased blurring of the lines between “research” and “treatment.” It distributes responsibility beyond physician-investigators to encompass policy makers, trial sponsors, consumer groups and patients themselves, and stresses the vital role of the courts to preserve the legal distance between “research” and “therapy.”

George Tomossy is a Lecturer at the Faculty of Law, University of Sydney, and in the final year of his doctoral research degree on the topic of Human Research Regulation. A past recipient of the Ross Waite Parsons Scholarship, he has published several articles and book chapters in his primary area of interest, and is co-editor of a number of books, including a trilogy of volumes on Ageing (Kluwer, 2001), Human Experimentation and Research (Ashgate, 2003) and Globalization and Health (Springer, forthcoming). He is the Executive Director of the International Academy of Law and Mental Health and was a principal organiser of the 28th International Congress on Law and Mental Health, which was held in Sydney in October 2003.

Constructions of Disability and Illness

Chair: Associate Professor Roger Magnusson
Faculty of Law, University of Sydney

‘Constructing “Control” Over Anorexia Nervosa’

Terry Carney, Faculty of Law, University of Sydney
(Paper co-authored with Mim Ingvarson and David Tait)

Anorexia nervosa is a chronic, relapsing condition, often characterised by denial of illness and rejection of treatment interventions. Previous work has shown that while law can compel treatment, it is rarely invoked, though it can be deployed strategically to motive acceptance of treatment. Instead it has been found that control and management is exercised diffusely (in many civil settings) and through disciplinary practices embedded in everyday clinic and community life, such as daily routines of eating and washing, culminating in self-management. This paper concentrates on the way anorexia is “constructed” in sociological terms and the sociological transformation of “identity” as it relates to the medico-legal trajectory of “acceptance” of the condition or of particular management regimes, using Goffman’s concept of 'moral careers' and Foucault's insights into disseminated power and self-management.

Terry Carney is Professor of Law at the University of Sydney (1991-), specialising in welfare law. Terry was Head of the Department of Law between 1992 and 1995 and is currently Director of Research in the Faculty. He is a Board member and President (previously General Secretary) of the International Academy of Law and Mental Health, and a past chair both of the National Advisory Council on Social Welfare and the Board of the Institute of Family Studies. The Australian reporter to the Max Planck Institute of Foreign and Comparative Social Law (Munich), he serves on the editorial Board of journals such as the International Journal of Law and Mental Health, Current Issues in Criminal Justice, and the Elder Law Review, and on Kluwer’s International Library of Ethics, Law and the New Medicine. The author of nearly a dozen books/monographs and around a hundred academic papers, he and his colleagues are completing a book for Nova Science NY, reporting findings of a three year Australian Research Council funded study into the regulation of anorexia. Professor Carney has
chaired various Government enquiries (including Victorian enquiries on Child Welfare Practice and Legislation (1982-84), on Health Law (1986-87)) and was a member of Australia’s pioneering enquiry into Adult Guardianship (1980-82). He is the longest serving member of the Social Security Appeals Tribunal, and a founding Director of the National Children and Youth Law Centre. He is currently working on an ARC Linkage grant project “Mental Health Tribunals: Balancing fairness, freedom, protection and right to treatment?”

‘Social Well-Being for All: Disentangling Disability and Health’

Lee Ann Basser, Faculty of Law, La Trobe University

The World Health Organisation defines health as “a state of complete physical and social well-being and not merely the absence of disease or infirmity.” This definition recognises the importance of the social constituents of health: access to shelter, food, clean water, clothing, education, employment, an adequate standard of living and so on. At the same time implicit in the definition is the idea that where disability is present, health and therefore social well-being are lacking. This is consistent with traditional approaches to disability which treat disability as a medical condition, a deviation from bio-medical norms. This equation of disability with ill-health is continued in the International Classification of Functioning, Disability and Health (ICF, WHO 2001) despite the recognition that environmental factors may contribute to disability and disability continues to be viewed as “individual deficit.” The consequence of viewing disability in this way is that people with disabilities are treated as outsiders and disability is seen as an issue of health status where the well-being of the individual and the community is achieved through treatment, rehabilitation and preventative measures.

By contrast, more recent understandings of disability, incorporated in the social model of disability (Oliver, 1990) and the human rights approach to disability (Jones & Basser Marks, 2000; Rioux, 1994) recognise that disability is not internal to the individual but is the external response to difference. Disability is socially produced and what is disabling is a complex array of conditions, activities and relationships created by the social and political environment. The social model rejects the traditional (individual deficit) understanding of disability, which is exposed as a form of biological determinism. Disability and the differential treatment of people with disabilities are seen to arise in the context of social, political and cultural practices. Building on the insights of the social model, the human rights approach starts from the point of view of the universal entitlement of all people to rights, equality and justice. What follows is that disability is an issue of social status rather than one of health status. Strategies for addressing disability focus on the removal of barriers to participation in society and supports and accommodations that facilitate inclusion in society. Social well-being is no longer defined as the absence of disability but as a marker of inclusion and equality. Taking the human rights approach as the framework of analysis, this paper seeks to disentangle disability from health and to move towards the realisation of equality of social well-being.

‘If Only Killing Me Softly Were All There Were To It: Law and the Construction of End of Life Interventions’

Derek Morgan, Faculty of Law, Cardiff University, UK

This paper considers the approach of Australian and English law to the related subjects of assisted killing, suicide, euthanasia and issues of withholding and withdrawing treatment. It takes as its point of departure traditional arguments about sanctity of life, notes the increasing subordination of that to appreciations of autonomy and dignity and considers and applies the analysis of Roger Brownsword and Deryck Beyleveld in Human Dignity in Bioethics and Biolaw and Onora O’Neill in Autonomy & Trust in Bioethics.

In each case the paper reviews the character of the subject of the supposed intervention: what does the common law have to say of the person engaged in the process of death by choice, whether that choice is one’s own or that of others making decisions on behalf of the dying person.

Derek Morgan is Professor of Health Care Law & Jurisprudence at Cardiff Law School, Wales and Visiting Senior Fellow at Melbourne Law School. He has taught and lectured widely throughout Europe and in Australia, Canada and the USA. He is a member of the British Medical Association’s Medical Ethics Committee and of the Ethics Committee of the Royal College of Physicians. From 2003–05 he was a Special Legal Advisor to the UK House of Commons Science & Technology Committee in its investigation Human Reproductive Technologies and the Law.