

Introduction

Belinda Bennett, Terry Carney & Isabel Karpin

Within contemporary society the meaning of “health” is increasingly contingent and contested. Categories and boundaries that once seemed self-evident have been reformed in the face of new social, scientific and economic realities. The construction and reconstruction of health has important implications for the development of law and policy. This book explores these themes, analysing the ways in which the meanings of health are constructed in contemporary society and the significance of those constructions for policy development.

Globalisation and Health

At the macro level, the economic and social forces associated with globalisation shape the lived realities of health for the world’s people. The first two chapters of the book analyse the impact of the international movement towards increasing globalisation on the conceptualisation and regulation of health.

In her chapter, Belinda Bennett examines the way in which health and rights are constructed in the context of the contemporary globalised environment. The increasing globalisation of health is reflected in international declarations and standards. However, the challenge of distilling core values is considerable, given the diversity of cultural and economic groupings across the globe. In addition, our conceptions of health and rights evolve with technological developments. Bennett explores this through three themes: first, the relationship between wealth and health which affects access to social infrastructures and the probability and impact of disease; secondly, the evolving nature of the relationship between health and disease; and thirdly, the relationship between the national and the international, and the

combination of national and international legal and social institutions that shape health. Bennett calls for work towards greater definition of the content of health rights and greater engagement with the issues associated with these concepts in a globalised world.

In Chapter 2 Thomas Faunce, Susannah Jefferys and Kellie Johnston discuss the role of multilateral and bilateral trade agreements in shaping domestic health policies. The authors outline the construction of the Pharmaceutical Benefits Scheme and its reconstruction through the *Australia–US Free Trade Agreement*, including consideration of possible health policy disputes and dispute resolution. The authors analyse the medicines-related provisions of the *Australia–US Free Trade Agreement* as a case study in order to explore the hypothesis that trade agreements represent a new tier of regulatory architecture, influenced by private interest lobbying backed by the threat of trade disputes. The authors contend that the problems surrounding the use of bilateral trade agreements to compel changes in domestic health policy are a threat to the sustainability of the global trading system.

Individuals and Health

The construction of health at the level of individuals is considered in Chapters 3-6. These four chapters investigate the challenge of balancing the roles for private individuals and for public institutions, such as law and the state, in the context of decisions about health.

Estair Van Wagner, Roxanne Mykitiuk and Jeff Nisker discuss the impact of new health-related technologies on the construction of embryos in their chapter, “The ‘Affected’ Post-Preimplantation Genetic Diagnosis Embryo”. New technologies, such as pre-implantation genetic diagnosis (PGD), give rise to new ways in which to view and characterise embryos. The authors explore these new characterisations, specifically the meaning attributed to descriptors such as “affected” and “unaffected” when applied to embryos. They consider how these terms influence concepts of “health” and “disability”. The authors’ research reveals that the characterisation of an embryo is affected by its intended use. For instance, is it intended for

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reproductive or research purposes? They also analyse the weight accorded to different stakeholders' perspectives under the various regimes. After examining the characterisation of embryos, the authors ask whether determinations of permissible uses of pre-implantation genetic diagnosis should be left largely in the private realm and if so, whether certain perspectives should be privileged above others (for example, the perspectives of clinicians to the disregard of those seeking PGD)?

The tension between state-based interventions and individual responsibilities for health is further explored in Chapter 4 by Wendy Rogers. Her chapter investigates the extent to which the individual, as opposed to the state, should be responsible for protecting his or her own health and the health of others. Drawing attention to the benefits and detriments associated with individual-centric and state-based health initiatives, Rogers investigates how to give appropriate recognition to the autonomy of individuals and avoid paternalism, while still acknowledging the power of the state in its ability to alter the environment so as to promote the health of individuals and the population. Applying Gostin's five criteria regarding state intervention, Rogers argues that state interventions for obesity can be justified.

In Chapter 5, Isabel Karpin considers the ways in which certain forms of body modification are considered matters of individual choice, while others are considered appropriate to the domain of state regulation and prohibition. Karpin considers radical, cosmetic, therapeutic and enhancing body modifications and interrogates the way in which cultural and ideological determinations of what is "natural" when unexamined become the normal. These ideas of the "normal" body are then internalised and pursued by individuals, enabling them to paradoxically construct their bodies so as to appear "naturally normal". Alongside these internalised regimes, legal regulation of such modifications further instructs us about which human traits are socially desirable and "normal".

Kristin Savell examines the role and relevance of the criminal law in cases involving the termination of pregnancy for disability in Chapter 6. Savell focuses discussion on the issues raised by two well-publicised cases of third trimester abortion in the UK and Australia, including the legal meaning of "serious disability", the proper construction of abortion offences, and the

relevance of law to clinical reproductive decision-making. Judgment on these questions is increasingly complex, influenced by biomedical techniques and competing ethical values. The unsuccessful attribution of criminal responsibility in both cases highlights the diminishing reach of the criminal law. Savell concludes that legal judgment may be being supplanted by biomedical and clinical judgement and that prospective mothers are themselves turning into bioethicists.

Emerging Issues in Health Research

Emerging issues in health research are examined in Chapters 7-9. The issues raised in these three chapters have implications for the ways in which developments in health research shape public conceptions of health.

In his chapter, David Healy explores the way in which pharmaceutical funding, strategically placed in academia, has leveraged a change in society that has transformed the way patients understand and express their most intimate experiences, and the way the physicians view those experiences. Healy compares case studies globally to ascertain the role of media editors, advertising, the market and companies, in a pattern of what he calls "disease mongering". Healy examines how the marketing of certain conditions such as osteoporosis, erectile dysfunction, ADHD and bipolar disorder leads to the use of hormone replacement therapy, Viagra, Ritalin and "mood-stabilisers". Healy asserts that changes of "label" seem capable of affecting significant parts of the overall experience such as anxiety or depression, and the transformation of one into the other. Critically, Healy discusses the emergence of privatised research and the ramification of company control of clinical trials and the production of scientific literature.

In Chapter 8, Margaret Otłowski explores the crucial role of public trust in human genetic research. Human genetic research is a particularly sensitive area of health research and is dependent on the altruistic provision of human genetic samples by members of the public. Although the interests of the individual are frequently viewed as competing with the public interest in promoting health research, the author asserts that

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there are strong public interests in safeguarding individual rights and preserving public trust in health research. These public interests have significant implications for regulatory frameworks governing health research. The author identifies several complexities, challenges and impediments to public trust, and proposes strategies for maintaining public trust in human genetic research.

In their chapter, Raymond De Vries, Trudo Lemmens and Charles Bosk unpack the ostensible objectivity of evidence-based medicine, revealing how structural, cultural and political forces “inform” the evidence underlying evidence-based medicine. The authors analyse the influence of pharmaceutical companies on the conduct and reporting of clinical trials, the conduct of obstetric science in the Netherlands which is characterised by a prevalence of home-births, and The Institute of Medicine’s attempt to shape policies to reduce “preventable adverse events”. Their analysis lends empirical support to the critiques of evidence-based medicine arising from the social sciences, and compels greater scrutiny of the threats to the integrity of the objective evidence underlying evidence-based medicine.

Constructions of Disability and Illness

The final set of chapters analyse some of the social forces at work in the construction of disability and illness, in various spheres – including in shaping understandings of such concepts by the public, by individual patients, by the courts, and by international bodies.

In Chapter 10, Patricia Peppin examines the construction of health, disease and drugs through the “information” generated for public consumption by the promotional activities of the pharmaceutical industry. The constructed perceptions of drugs have been challenged by subsequent revelations, such as the adverse effects of certain antidepressants and the marketing of certain painkillers. Peppin analyses the means by which such “information” about drugs is exposed, including: through litigation brought against pharmaceutical companies; investigation by government officials, investigative journalists and researchers; and confession by pharmaceutical companies. These sources

of information have provided a critical challenge to the construction of health benefits by pharmaceutical companies and represent a preliminary step towards improved protection of patient safety.

In Chapter 11 Terry Carney, Miriam Ingvarson and David Tait explore the construction of coercion and control as “experienced” by patients during treatment of severe anorexia nervosa. The authors canvas sites and processes of the construction of personal identities for anorexia patients, and explore the forces that shape the construction of new identities more favourable to recovery. The authors focus on the construction and management of an anorexic “identity” within the medico-legal setting, in which treatment can be authorised under adult guardianship or mental health laws where the condition of patients has reached a perceived critical point. The authors relate findings from their study of the construction of “control” by formal and informal measures at different stages of clinical management of anorexia. The authors reveal that in the medico-legal setting, the identity of anorexia patients is constructed and transformed by a multiplicity of social, and occasionally legal, controls.

Ian Freckelton’s chapter reviews the development of litigation concerning post-traumatic stress disorder. Freckelton charts the different phases in this development, with particular reference to the litigation arising out of the collision between HMAS *Melbourne* and HMAS *Voyager*. These different phases have been characterised in the courts by varying approaches to the use of clinical diagnostic criteria and judicial scepticism towards the conflicting evidence of plaintiffs and expert witnesses. The author demonstrates that a period of over-diagnosis without application of diagnostic criteria culminated in a backlash against post-traumatic stress disorder claims and civil liability reforms intended to restrict claims for pure psychiatric injury, with the consequence of disadvantaging victims of psychiatric injuries compared to victims of somatic injuries.

Finally, in Chapter 13 the construction of health and the right to health is considered by Lee Ann Basser from a disability rights perspective. Basser highlights the link between the concepts of health and disability, as embodied in definitions put forward by the World Health Organization (WHO), and reveals

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that this understanding of disability reflects the individual, or medical, model of disability, in which disability is equated with ill-health. Basser contrasts this model with alternative models for understanding disability including the social model of disability, the minority group rights analysis, and finally a human rights approach to disability. The human rights approach is reflected in the recent *International Convention on the Rights of Persons with Disabilities*, which represents a paradigm shift in which individuals with disabilities are viewed as subjects of rights rather than objects of treatment and social protection. In her analysis, Basser disentangles the concepts of disability and health, such that under a human rights model of disability health is viewed as an aspirational goal for all individuals.

As the contributions to this volume demonstrate, the terms and concepts which form the basic building blocks of dialogue about health are in a constant state of flux. While the forces in play may differ, and the pace of change is varied, this is the wider frame within which public policy debate about health (and illness or disability) is conducted; just as it informs many discussions of supposedly narrow, technical issues within clinical medicine, the law and medical science.