Symposium Articles

752
INTRODUCTION
John-Stewart Gordon and Jerome Bickenbach

754
Is Inclusive Education a Human Right?
John-Stewart Gordon

In this article, I question the general idea that inclusive education—i.e., to teach all students in one class—is a moral human right. The following discussion shows that the widespread view in disability studies that there is a moral human right to inclusive education can be reasonably called into question by virtue of the proposed counter arguments, but without denying that inclusive education is of utmost importance. Practically speaking, the legal human right to inclusive education is of great practical value for impaired students, and for their basic right to be free from discrimination in education, since their concern thereby gains great legal and moral force. But, theoretically speaking, this particular human right lacks an attainable consensus concerning proper moral justification.

768
Disability and Capability: Exploring the Usefulness of Martha Nussbaum's Capabilities Approach for the UN Disability Rights Convention
Caroline Harnacke

I explore the usefulness of Martha Nussbaum’s capabilities approach in regard to the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD aims at empowering people with disabilities by granting them a number of civil and political, but also economic, social and cultural rights. Implementing the CRPD will clearly be politically challenging and also very expensive for states. Thus, questions might arise as to whether the requirements set in the CRPD can be justified from an ethical perspective. I will first investigate if Nussbaum’s capabilities approach provides support for the rights claimed in the CRPD. Second, I will investigate to what extent Nussbaum’s capabilities approach is a useful tool to set priorities among rights in the course of the implementation of the convention. This is an urgent question because seen realistically, it will not be possible to realize all rights at once and thus some rights need to receive greater priority than others. I will argue that the capabilities approach can be regarded as supporting the rights specified in the CRPD, but that it proves unable to guide the implementation process due to an insufficient grounding of the capabilities. Employing the capabilities approach thus leads to only limited results.

781
Human Rights, Civil Rights: Prescribing Disability Discrimination Prevention in Packaging Essential Health Benefits
Anita Silvers and Leslie Francis

This article explores rights-based approaches to protecting disabled people against inequities in access to health care services. Understanding health care as a human right, as is found in the UN Convention on the Rights of People with Disabilities (CRPD), fails to provide theoretical machinery for responding to certain pressing challenges. An alternative account, understanding health care as a civil right, proves more promising. This latter approach then is applied to the right to health care under the U.S. Affordable Care Act (ACA), which contains provisions that could be antithetical to, and thus fail to comply with, the nondiscrimination standard of meaningful access to health care benefits.

792
Nandini Devi

Making decisions is an important component of everyday living, and issues surrounding autonomy and self-determination are crucial for persons with intellectual disabilities. Article 12 (Equal Recognition before the Law) of the UN Convention on the Rights of Persons with Disabilities addresses this issue of decision-making for persons with disabilities: the recognition of legal capacity. Legal capacity means recognizing the right to make decisions for oneself. Article 12 is also moving in the direction of supported decision-making, as an alternative to substituted decision-making. The objective of this paper is to show conceptually the connection between supported decision-making and the preservation of personal autonomy for persons with intellectual disabilities. This paper discusses supported decision-making based on Bach and Kerzner’s model: (a) legally independent status, (b) supported decision-making status, and (c) facilitated decision-making status. Arguments will be made based on John Stuart Mill’s concept of autonomy and arguments against it using Sarah Conly’s argument for paternalism.
807
Expanding the Horizons of Disability Law in India: A Study from a Human Rights Perspective
Tushti Chopra

Disabled “differently abled” persons by virtue of being human have the right to enjoy human rights to life, liberty, equality, security, and dignity. However, due to social indifference, psychological barriers, a limited definition of “disability” entitling protection of law, and a lack of proper data, disabled persons in India remain an invisible category. Although several laws exit to ensure their full and effective participation in society, they remain insufficient as they are primarily based on the government’s discretion. At the same time, whenever the judiciary finds an opportunity, it acts as a real protector of disabled persons, but it is not feasible to knock on the door of the judiciary for every request. Interestingly, various civil societies and human rights activists have occasionally asserted the rights of the disabled. However, unless the foundation stones of law are fortified, disabled persons cannot fully realize their rights. It is high time to enact effective laws, with timely implementation, to protect their interests and empower their capabilities that are based on a “rights-based approach” rather than on the charity, medical, or social approaches. Thus, the horizons of law must be expanded to provide a “human friendly environment” for all of the disabled to overcome the barriers that impair their development.

821
Disability, “Being Unhealthy,” and Rights to Health
Jerome Bickenbach

Often advocates for persons with disabilities strongly object to the claim that disability essentially involves a decrement in health. Yet, it is a mystery why anyone with an impairment would ever deny, or feel uncomfortable being told that, their impairment is at bottom a health problem. In this paper, I investigate the conceptual linkages between health and disability, relying on robust conceptualizations of both notions, and conclude it makes no conceptual sense to insist that a person can be seriously impaired yet still be, or become, “perfectly healthy.” But that cannot be the end of it since this kind of error is commonly made, and I try to tease out the reason why not only disability advocates but agencies like the WHO and the CDC fall victim to it. I conclude by conceding that there are indeed sound political reasons for being cautious about the alignment of disability and ill-health, but suggest that the price we pay in conceptual confusion may be too high to allow those reasons to dictate policy.

841
The Ethics of Intellectual Property Rights in an Era of Globalization
Aakash Kaushik Shah, Jonathan Warsh, and Aaron S. Kesselheim

Since the 1980s, developed countries, led by the United States and the countries of the European Union, have sought to incorporate intellectual property rights provisions into global trade agreements. These countries successfully negotiated the World Trade Organization’s 1994 Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), which required developing countries to adopt intellectual property provisions comparable to developed countries. In this manuscript, we review the policy controversy surrounding TRIPS and examine the two main ethical arguments articulated in its support — a theory of natural rights and a utilitarian argument. We contend that these theories provide insufficient bases for an intellectual property rights regime that compromises access to essential medicines in the developing world. While the policy community has engaged in active debate around the policy effects of TRIPS, scholars have not thoroughly considered the full ethical underpinnings of those policy arguments. We believe that a more robust understanding of the ethical implications of the agreement should inform policy discussions in the future.

852
Supporting Second Victims of Patient Safety Events: Shouldn’t These Communications Be Covered by Legal Privilege?
Mélanie E. de Wit, Clifford M. Marks, Jeffrey P. Natterman, and Albert W. Wu

Adverse events that harm patients can also have a harmful impact on health care workers. A few health care organizations have begun to provide psychological support to these Second Victims, but there is uncertainty over whether these discussions are admissible as evidence in malpractice litigation or disciplinary proceedings. We examined the laws governing the admissibility of these communications in 5 states, and address how the laws might affect participation in programs designed to support health care workers involved in adverse events. We found that privilege is uneven from state-to-state, and also unclear. Ambiguity alone could have a chilling effect on Second Victim programs. We propose legislation to protect volunteer and health care worker communications provided by peer counselors, or failing this, updating of statutory provisions to explicitly include these communications within the ambit of existing protections. Enhancing protections could help to foster an environment of healing for both patients and caregivers.
Another Look at the Legal and Ethical Consequences of Pharmacological Memory Dampering: The Case of Sexual Assault
Jennifer A. Chandler, Alexandra Moggyros, Tristana Martin Rubio, and Eric Racine
Research on the use of propranolol as a pharmacological memory dampening treatment for post-traumatic stress disorder is continuing and justifies a second look at the legal and ethical issues raised in the past. We summarize the general ethical and legal issues raised in the literature so far, and we select two for in-depth reconsideration. We address the concern that a traumatized witness may be less effective in a prosecution emerging from the traumatic event after memory dampening treatment. We analyze this issue in relation to sexual assault, where the suggestion that corroborating evidence may remedy any memory defects is less likely to be helpful. We also consider the clinical ethical question about a physician’s obligation to discuss potential legal consequences of memory dampening treatment. We conclude that this latter question reflects a general problem related to novel medical treatments where the broader socio-legal consequences may be poorly understood, and suggest that issues of this sort could usefully be addressed through the promulgation of practice guidelines.

The Right to Language
Tom Humphries, Raja Kushalnagar, Gaurav Mathur, Donna Jo Napoli, Carol Padden, Christian Rathmann, and Scott Smith
We argue for the existence of a state constitutional legal right to language. Our purpose here is to develop a legal framework for protecting the civil rights of the deaf child, with the ultimate goal of calling for legislation that requires all levels of government to fund programs for deaf children and their families to learn a fully accessible language: a sign language.

Adherence to the Request Criterion in Jurisdictions Where Assisted Dying Is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland
Penney Lewis and Isra Black
Some form of assisted dying (voluntary euthanasia and/ or assisted suicide) is lawful in the Netherlands, Belgium, Oregon, and Switzerland. In order to be lawful in these jurisdictions, a valid request must precede the provision of assistance to die. Non-adherence to the criteria for valid requests for assisted dying may be a trigger for civil and/or criminal liability, as well as disciplinary sanctions where the assistor is a medical professional. In this article, we review the criteria and evidence in respect of requests for assisted dying in the Netherlands, Belgium, Oregon, and Switzerland, with the aim of establishing whether individuals who receive assisted dying do so on the basis of valid requests. We conclude that the evidence suggests that individuals who receive assisted dying in the four jurisdictions examined do so on the basis of valid requests and third parties who assist death do not act unlawfully. However, further research on the elements that may undermine the validity of requests for assisted dying is warranted. More research on the reasons why requests for assisted dying are refused is also desirable.

Currents in Contemporary Bioethics
Predictive Genetic Testing of Children and the Role of the Best Interest Standard
Lainie Friedman Ross
The “best interest standard” is the guidance principle for pediatric healthcare in the United States (US) and the United Kingdom (UK). In the UK, the best interest standard may also be used as an intervention principle when parents make good but non-ideal decisions whereas intervention in the US requires a determination of abuse or neglect. I examine whether and how the different uses of the best interest standard influence predictive genetic testing of children.

Teaching Health Law
A Place for All at the Global Health Table: A Case Study about Creating an Interprofessional Global Health Project
Virginia Rowthorn
This essay is a reflection on the “why” and “how” of creating an interprofessional global health project, with specific focus on the challenges of incorporating law students into this type of educational activity.

Book Review
Conflicts of Interest and the Future of Medicine: The United States, France and Japan by Marc A. Rodwin
Eric G. Campbell