

Genetics, Law and Society: Regulating New Genetic Technologies

Authors : Aisling De Paor

Abstract : Scientific and technological developments are driving genetics and genetic technologies into the public sphere. Scientists are making genetic discoveries as to the make up of the human body and the cause and effect of disease, diversity and disability amongst individuals. Technological innovation in the field of genetics is also advancing, with the development of genetic testing, and other emerging genetic technologies, including gene editing (which offers the potential for genetic modification). In addition to the benefits for medicine, health care and humanity, these genetic advances raise a range of ethical, legal and societal concerns. From an ethical perspective, such advances may, for example, change the concept of humans and what it means to be human. Science may take over in conceptualising human beings, which may push the boundaries of existing human rights. New genetic technologies, particularly gene editing techniques create the potential to stigmatise disability, by highlighting disability or genetic difference as something that should be eliminated or anticipated. From a disability perspective, use (and misuse) of genetic technologies raise concerns about discrimination and violations to the dignity and integrity of the individual. With an acknowledgement of the likely future orientation of genetic science, and in consideration of the intersection of genetics and disability, this paper highlights the main concerns raised as genetic science and technology advances (particularly with gene editing developments), and the consequences for disability and human rights. Through the use of traditional doctrinal legal methodologies, it investigates the use (and potential misuse) of gene editing as creating the potential for a unique form of discrimination and stigmatization to develop, as well as a potential gateway to a form of new, subtle eugenics. This article highlights the need to maintain caution as to the use, application and the consequences of genetic technologies. With a focus on the law and policy position in Europe, it examines the need to control and regulate these new technologies, particularly gene editing. In addition to considering the need for regulation, this paper highlights non-normative approaches to address this area, including awareness raising and education, public discussion and engagement with key stakeholders in the field and the development of a multifaceted genetics advisory network.

Keywords : disability, gene-editing, genetics, law, regulation

Conference Title : ICLS 2017 : International Conference on Law and Society

Conference Location : Boston, United States

Conference Dates : April 24-25, 2017