The Connected Self: The Ethics and Governance of the Genetic Individual

Posted on Wednesday 24th October 2012

Professor Widdows has a new book, ***The Connected Self: The Ethics and Governance of the Genetic Individual*** **(http://www.amazon.co.uk/The-Connected-Self-Governance-Individual/dp/product-description/1107008603)** (Cambridge University Press). Due out in 2013, this book is about how to balance individual and communal models of ethics and argues that:

Currently, the ethics infrastructure – from medical and scientific training to the scrutiny of ethics committees – focuses on trying to reform informed consent to do a job which it is simply not capable of doing. Consent, or choice, is not an effective ethical tool in public ethics and is particularly problematic in the governance of genetics. Heather Widdows suggests using alternative and additional ethical tools, and argues that if individuals are to flourish it is necessary to recognise and respect communal and public goods as well as individual goods. To do this she suggests a two-step process – the 'ethical toolbox'. First the harms and goods of the particular situation are assessed and then appropriate practices are put in place to protect goods and prevent harms. This debate speaks to core concerns of contemporary public ethics and suggests a means to identify and prioritise public and common goods.

Reviews of *The Connected Self*

In this impressive book, Heather Widdows elaborates her own distinctive critique of a bioethics that focuses only on respecting the informed choices of individuals. According to Widdows, in the light of the connections (including genetic connections) between humans, it will not do simply to prioritise individual (self-serving) choice. Account must be taken, too, of the interests of third parties, of groups and of communities. If bioethics is to be less blinkered, it needs a new approach—one that collects the required 'tools' and then applies them in a way that is responsive to the full range of material harms and goods. *The Connected Self* is a compelling read.
Roger Brownsword, Professor of Law, Kings College, London and Chair of UK Biobank Ethics and Governance Council

The book advocates a paradigm shift in bioethics. With a battery of philosophical arguments, Widdows soon convinces the reader that our current ethical framework, the choice model, has to go. Then she builds on the inadequacies of the choice model to put forward a new original approach which does a better job at safeguarding what we care about. The most amazing thing is that Widdows achieves all of this in a book that is informative, scholarly and yet extremely accessible and never dull.
Lisa Bortolotti, Reader in Philosophy, Birmingham University

The depredations of neo-liberalism have exposed the inadequacy of the idea of the individual underlying that ideology of egoism. In setting out how genetics makes ethical individualism redundant -- itself an important and timely argument -- Heather Widdows at the same time puts neo-liberal "morality" firmly in its place.
Bob Brecher, Professor of Ethics, University of Brighton

This book is a 'must-read' for anyone who is interested in the ethics and governance of science. Widdows' argument for the 'connected self' not only clearly demonstrates the need for new ways of thinking about contemporary issues in genetics and genomics, but also highlights the ways in which ethics itself co-evolves with science.
Ruth Chadwick, Distinguished Research Professor, Cardiff University and Director of Cesagen

This book, rich in arguments and examples yet written so clearly and passionately that it should be compulsory reading for everyone, provides a strong and urgently needed call to 'clean up our act' as regards the ethical governance of genetics.

After making a strong evidence-based case that the genetic self is the connected self, Widdows develops a powerful critical analysis of the individualist choice model at work in much of current bioethics, a model which clearly does not protect individuals against exploitation and in reality frequently implies a total lack of ethical safeguards. At the same time, she highlights the unconvincing nature of anti-paternalism arguments, which are based on the assumption that the only significant good is individual choice and which, in reality, render any meaningful ethical reflection and debate impossible. Yet Widdows does not make the mistake of adopting a perspective that only considers group interests; rather she insists that individuals as well as groups need to be recognized and protected. The ethical toolbox she defends, based on her careful and highly informed analysis, has great potential to enable us to identify the most important individual and group goods, which are largely invisible in the currently dominant choice model, as well as to subsequently adopt specific practices that protect these goods and prevent the most serious harms. Another major advantage of the toolbox Widdows offers us, is its dynamic nature and its capacity to take into to account the specificity of particular contexts as well as developments in science and technology.

This book convincingly argues that the ethical toolbox is to be preferred over the benefit sharing and trust models, while not underestimating the difficulties involved in the toolbox model. One of the greatest strengths of Widdows' arguments, as compared with other pleas for empowering individuals in the genetic era, is that she shows the reader that it is possible to allow research participants significant involvement in and appropriate control over the use of the material derived from their bodies, without granting them property rights.

Throughout this book, it is clear that Widdows' ultimate concern is to help develop a model that will get us as closely as possible to a world in which research participants, anywhere in the world, can have their expectations met and will neither feel cheated nor be cheated. Reading this book reminded me why I became an ethicist.
Sigrid Sterckx, Professor of Ethics, Ghent University

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