A Book Review
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Board Chairman, The Tennessee Center for Bioethics & Culture *Human Flourishing in an Age of Gene Editing*Erik Parens and Josephine Johnston, Editors
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As we now live in a time when our genetic code can be altered, whether for better or worse, how should we think about what is best for ourselves? How can we as a human species and as individuals flourish? These are the questions posed in the new volume, <u>Human</u> Flourishing in an Age of Gene Editing. The essays here are interactive, frequently referencing one another, as the authors from a variety of professional backgrounds tackle the relationship of new genetic technique to human flourishing. The protagonist is CRISPR technology, introduced in 2012 as a huge leap forward in genetic engineering, which has been around since the 1970's but now has the ability to make changes, or edits, to as large or small a part of a gene as a scientist may desire. The potential ranges from curing inherited disease to human cosmetic enhancement. The authors in this series contemplate the larger social and moral implications of the new abilities that we have. The initial essay, written by a professor and bioethicist with a genetic physical disability who has flourished in her chosen field, sets the book's tone. Rosemarie Garland-Thomson emphasizes that she and three colleagues with comparable inherited issues have had the ability to do well and achieve distinction "not in spite of our disabilities, but rather with our disabilities." She alludes to the opportunities that their problems have afforded, rather than to setbacks. This perspective highlights the view that humans do not necessarily need to be changed to do well. Flourishing is a matter not of fixing disabilities, but rather allowing people to grow with them. So before society decides that every aberration in the genetic code should be corrected, attention should be focused on how to come around those who have perceived difficulties and how to allow their greatest potentials to come forward.

Human Flourishing in an Age of Gene Editing



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This author recognizes that complete elimination of some conditions such as Huntington's disease may be a desirable thing, but the caveat here is the possibility of adverse unintended consequences of genetic manipulation in doing so. Moreover "what's wrong with making people through genetic engineering is that someone else's priorities ... govern the selections either for or against the traits that make up our unique personhood." John H. Evans, Co-director of UC San Diego's Institute for Practical Ethics, offers an analysis of the development of bioethics over the last 50 years that helps one understand the potential as well as the difficulties in ongoing discussion of these issues. Whereas theologians and secular philosophers initiated serious bioethical discussion early on, in the 1970's needs arose regarding how to address certain practical problems in medicine such as informed consent, guidelines for human research, and how to think about new things like cloning and genetic modification. Basic principles were hammered out – beneficence, doing no arm, respecting autonomy of individuals, and justice. These ethical principles served well in developing public policy on a number of things. But Evans argues that these constituted a "thin" form of bioethics, a barebones approach that left out deeper, more nuanced discussion, something he calls "thick" bioethics. What is missing is a thoroughgoing conversation on the ends and purposes that remain after the principles are satisfied; that is, what goals we really need to pursue to attain human flourishing.

One way to have a "thicker" conversation is to maintain discussion of the concept of human dignity. Such a focus helps to get beyond the value of autonomy, which enables us to respect human beings' choices, to a respect for what human beings are, independent of what they choose or can do. Dignity has been espoused in the modern era by the United Nations Commission on Human Rights, as the basis of rights and political goods in general, as well as by Roman Catholic writers who spoke of dignity rooted in the divinely created soul, which then mandated a greater pastoral concern of the church for all of humanity. A great deal of dignity discussion came from the President's Commission on Bioethics during the tenure of President George W. Bush, under leadership of Leon Kass. The "essence" of living things came under scrutiny with the specter of human cloning after publicity about Dolly the sheep, and great concerns arose about the use of human stem cells, especially when destruction of human embryos might be involved. Kass was concerned that new technology was "taking us down the dehumanizing path toward a brave new world." Others however have derided the use of human dignity as political opportunism, or moralism to control the shape of the debate. But essayist Gaymon Bennett writes that, in considering

gene editing, "we must ask not only what we want to achieve in transforming ourselves through the manipulation of our bodies, but also what such transformations might violate." The essays here explore a wide range of topics, such as how to maintain human authenticity, how to value humans in their natural state, and what a "good parent" should do when faced with new choices in determining characteristics in their offspring. Social pressures and parental inclinations to use anything that would help their children drive interest in gene editing, and companies that offer genetic testing are ramping up their offerings.

Two authors explore theological input into the bioethical discussion on gene editing. Celia Deanne-Drummond reviews the "beatific vision" originating from Thomas Aquinas, whereby certain virtues come only by the grace of God and culminate in a form of "practical wisdom," which is essential in approaching modern ethical dilemmas. Michael Burdett explores the biblical concepts of humans as created beings, hence made in God's image yet limited, and as children in God's family who are able to imitate Christ in bringing creativity and betterment to the world around them. Contrary to some secular opinions, Burdett makes a strong case for keeping religious voices in the public debate.

As grandfather of a young child with asthma, epilepsy and autistic tendencies, I have found myself enlightened and encouraged by this book. Our grandson is a delightful, active, cheerful soul. It is sobering to consider how things could possibly be different for a child like this in the future through the technology of gene editing. But to recognize the uniqueness of each individual person, created in a certain way, seems to be the higher ground. The "thicker" bioethical discussion in this book lends practical advice and wisdom in a cautionary way to those who would consider unlimited pursuit of new biotechnology. Gene editing is with us, will continue to develop, and will continue to provoke the interest of the public. The book is an excellent resource to help one to ponder whether there is a balance between the option of controlling our destiny and the stance of acceptance of ourselves as we are.