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Theme Article

Raising the Next Generation Bioethical Education for a Post-Genomic Age

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Biomedical advances during the past 40 years overhauled the experience for adults entering parenthood. Our abilities to detect, image, and quantify aspects of human development have revolutionized both prenatal care and the information exchanged between obstetricians and families. While these breakthroughs have offered a greater awareness of fetal health, they have also prompted new and complex bioethical questions. With the advent of prenatal testing for untreatable diseases — such as Edward's syndrome, Tay-Sachs disease, sickle-cell disease, cystic fibrosis, and Down syndrome — many prospective parents have found themselves thrust into personal debates over abortion before they even feel a first kick.

Now, a new surge in medical genetics flows from our ever-expanding knowledge of genotype-phenotype relationships and plummeting price points for innovative, "next generation" genetic technologies — creating even more tension than was foreseeable a few years ago. Questions over which genetic conditions should be probed and by whom pepper the field of bioethics. Opinions abound, but clear solutions have not yet surfaced. To complicate matters further, the first companies offering direct-to-consumer testing are already staking their claims in a burgeoning market that has developed a taste for genetic information, driving a general perception that more genetic data is always a good thing.

Precollegiate education has paid little attention to the bioethical underpinning of recent innovations. Without a deliberate commitment to bioethical education, confusion and divisiveness regarding genetic testing are likely to challenge harmony in our families and further polarize our already fragmented society.

Picture this: The year is 2020, and a couple wishes to start a family. They rejoice in their ability to conceive and celebrate the bright future they anticipate spending with their child. At their first prenatal visit, their elation is subdued as they peruse a confusing collection of pamphlets in their doctor's office on topics ranging from "stem cell banking" to "DNA copy number analysis." As this terminology becomes familiar territory for the couple, they notice an even more dizzying array of choices being advertised throughout the mainstream media, each promising to alleviate risk of potential suffering or increase odds for the health and well-being of their prospective offspring.

How will these two adults, who left formal studies of science behind them years before, navigate the sophisticated, genetics-based prenatal assessments on the market? How will they approach the moral decisions that shall inevitably accompany their options? Have they — and members of their support network — been prepared to engage in the thoughtful inquiry that may ultimately bring them peace of mind during an emotionally charged time?

Today's students will face these questions in their near future. Yet, are we educating this next generation — the parents of tomorrow — about the complex ethical issues they will confront in our post-genomic age?

Bioethical Education for the Next Generation

While the past 40 years of scientific achievements have generated a pressing need for careful discussion of bioethical issues, our society has shifted, regrettably, away from a standard tenor of inquiry that is reliably respectful and thought provoking. One need only to consider the examples set everyday by popular media, politicians, and corporations to recognize that our children will require extra support from their homes, communities, and schools to develop the ability to engage in thoughtful reasoning and discourse. A collaborative effort, including greater bioethical education at school, will enable our young adults to acquire the skills necessary for moral inquiry in a world where polemical, vituperative argument has emerged as an unfortunate cultural norm.

There is reason to be hopeful! We have developed reliable reproductive technologies that are capable of preventing a good deal of suffering for families with histories of devastating genetic disorders. And students today are extremely well versed in genetics compared to previous generations. Their greatest apparent need is a skill set useful for processing and discussing socially charged issues.

A collaborative effort, including greater bioethical education at school, will enable our young adults to acquire the skills necessary for moral inquiry in a world where polemical, vituperative argument has emerged as an unfortunate cultural norm.

Elective courses are attractive solutions for independent schools, and may provide a source of low-hanging fruit for early efforts to integrate bioethics into secondary curricula. At our school, Phillips Academy (Massachusetts), students choose from a range of interdepartmental offerings, each challenging them to synthesize knowledge across disciplines into clear views on complex issues. In *Humanity in the Post-Genomic Era*, for example, we begin with conception and consider the many functional milestones comprising embryogenesis and fetal development. Students are then asked to formulate their own ethical positions with regard to the acquisition of moral status in humans. From there, we consider the topic of human enhancement through an analysis of banned athletic interventions such as blood doping and steroid use. Students learn the biological basis of these enhancements as well as the socio-cultural contexts relevant to their use by today's professional athletes. To evaluate the potential impact of such enhancements on the integrity of sport, they learn to substantiate their philosophical claims through incorporation of both biological and sociological data. Finally, students investigate our most charged topic — prenatal genetic testing — and must formulate personal views on the role(s) that various forms of testing should serve in our society. The course challenges students not only to consider the ethical implications of scientific advances, but also to employ their knowledge of basic biology when justifying and critiquing moral claims.

While specialized electives are popular among students and faculty alike — offering young minds the opportunity to tackle exciting interdisciplinary topics and providing faculty members with a forum for meaningful interdepartmental collaboration — developing new courses can be an impractical route for many schools. We educators typically seek new ideas and resources to inform our pedagogy within an existing curriculum. The question, always, is how to most effectively integrate opportunities for multidisciplinary learning into ongoing "core" programs.

Here are some suggestions when it comes to bioethical discussions:

1 Remove politics and religion.

Open and respectful discussions on bioethical topics may be nested very effectively within more traditional units on reproductive and developmental biology. Instructors can encourage students to learn the biological basis of socially charged issues in a setting that is free of political or religious affiliation. With this experience in hand, students may then go on to develop their personal thoughts and beliefs in a more informed and substantiated manner.

2 Encourage students to explore without judgment.

Blogs or journals can help students approach sensitive topics. In our *Humanity* course, students post nightly reflections online, in a semi-private journal accessible only to their instructors. These journals offer students the space for much needed self-discovery and experimentation, providing a powerful complement to our more public classroom discussions.

3 Reintroduce humans back into the issue.

Case studies using a sampling of prenatal genetic testing scenarios, especially effective as a small-group activity, reinforce basic genetics and give students the opportunity to wrestle with moral questions straight from the real world. Case studies also illuminate the types of pressing bioethical concerns faced by families today, personalizing genetic dilemmas covered in the classroom.

4 Expose vulnerability of individual ethical positions.

Assignments that challenge students to detail their own moral positions while respectfully reporting the strengths and weaknesses of a variety of popular opinions support the development of informed moral inquiry in our young adults. In particular, it is the students' critical reflection of their own positions that enables them to build the strongest justifications for their thoughts and beliefs.

5 Role play: engaging alternative views.

Role-playing activities with topics ranging from abortion to embryo ethics are illuminating. Most high school students will typically begin such an exercise by attempting to "convert" fellow players to their point of view. Role swapping

allows students the chance to personally try on competing moral stances and, again, to find value in multiple points of view.

There is even more good news. We teachers have access to a generous amount of guidance from the bioethics community as we strive to effectively introduce moral investigations into our biology classrooms. Toolkits developed by The Hastings Center¹ as well as the National Institutes of Health² provide welcome support in this effort. In addition, bioethicists passionate about education have begun to form collaborative initiatives with local teachers to direct the incorporation of innovative educational goals as well as public awareness regarding the importance of bioethics education. As these types of collaborative efforts scale upward in size and number, early enthusiasm regarding bioethics education will ultimately be carried through to sustained reform.

Why do we need to engage these complex, sensitive topics? Because the parents of tomorrow — and their children — will be shaped by the public discussions we begin today.

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Notes

1. The Hastings Center, *New Choices, New Responsibilities: Ethical Issues in the Life Sciences* (Garrison, NY: The Hastings Center, 2005).
2. NIH Department of Bioethics and EDC, "NIH Curriculum Supplement Series: Exploring Bioethics," 2009, <http://science-education.nih.gov/supplements/nih9/bioethics/default.htm>.