

Reconciling Science and Society*

Tanya Williams**, Scott Siera**, and Arri Eisen***

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**Emory undergraduate fellows in Science & Society

***Senior Lecturer in Biology, Director of the Program in Science & Society of the Emory College Faculty Science Council and Director of the Science, Ethics, & Society Initiative in the Emory Center for Ethics

The Fourth National Undergraduate Bioethics Conference held at Emory University October 4-7th, 2001, marked the a stage in the vital conversation between science and society. Over 100 students and 40 professionals representing more than 30 institutions gathered in Atlanta. The conference was the first of its kind to explore applied ethics across multiple disciplinary fields, while simultaneously permitting intellectual interaction among distinguished scientists, clinicians, faculty and students from universities across the country.

This conference sought to build upon the achievements of the previous three conferences, also organized by and for students. Princeton University hosted the first conference, entitled Bioethics in the New Millennium, in February 1999. It brought together internationally recognized bioethicists and undergraduate students from around the United States. Effectively setting the tone for its successors, this conference focused on the role of bioethics in medicine, industry, and public policy. It featured lectures and panel discussions led by Francis Collins, Director of the National Genome Research Institutes of Health, Roy Vagelos, former Chief Executive Officer of Merck & Co, Inc., and other acclaimed speakers in the scientific field.

The success and enthusiasm generated by the first conference fueled the second National Undergraduate Bioethics Conference hosted by the University of Virginia in March 2000. This conference was designed to further facilitate dialogue between bioethicists and students who would set the ethical, legal, and social precedents for dealing with medical progress and health care in the new century. Extending the discussion topics of the previous conference, the second conference addressed stem cell research, new reproductive technologies, managed care and access to health care, and the ethical issues associated with the human genome project and cloning. The Third National Undergraduate Bioethics Conference held on the University of Notre Dame campus in March 2001, expanded the focus to include an examination of the effects of bioethics on varying aspects of health—physical, mental, and social. It

recognized that bioethics as a discipline has broadened its scope by studying how scientific advances and philosophy affect all areas of human life. The fourth conference took this idea one step further.

Acknowledging that bioethics—coined in the title of Van Potter’s 1971 book Bioethics: Bridge to the Future—as a discipline is less than forty years old, the fourth conference reminded society that bioethics also applies to matters outside the realm of medicine. If the public was asked which issues exemplify this emerging field, the majority would more than likely respond with a biomedical answer. Many people would be quick to point out ethical controversy surrounding United States medical research in third world countries, reproductive medicine and cloning, and the future of gene therapy. Quite possibly, a few would mention the struggle to define death in light of advancements in life-support technology and to determine what role, if any, a physician should play in the termination of life. While these issues are all critically important considerations for society, they do not succinctly represent the ethical dilemmas humanity faces in the present or future.

Too often, religious and ecological consequences of modern medical technology and research are overlooked. Contemporary health practices largely focus on fighting death and prolonging life. Breakthroughs in pathology and advances in therapy have extended the lives of many who, in the recent past, might have succumbed to diseases such as sickle-cell anemia and cystic fibrosis. On a different front, our ecosystem is already facing daunting problems stemming from overpopulation and crowding concerns. As researchers and clinicians continue to develop methods for prolonging life and prohibiting death, what will happen to the environment? We realize that human health and well being have many faces, all of which interact to maintain the balance of life. If we ignore issues that affect the spiritual, emotional, and environmental health of society, focusing primarily on mental and physical benefits, we are doing ourselves a great disservice. In preemptive fashion, the fourth undergraduate bioethics conference brought these questions to the surface, emphasizing the need to create a dialogue between the diverse elements of science and society.

The conference officially commenced with keynote speaker Dr. Glenn McGee, Associate Director for Education at the University of Pennsylvania Center for Bioethics, Associate Professor of bioethics, philosophy, and the sociology of science, and Editor-in-Chief of the American Journal of Bioethics. Dr. McGee spoke about the latest ethics, science, and policy issues surrounding embryonic stem cell research. Following this opening address, conference participants were invited to join panel discussions or go on ‘ethics on site’ field workshops at nearby locations. Field trip venues included the headquarters of The Centers for Disease Control and Prevention, The American Cancer Society, The Veteran’s Affairs Hospital, and Wesley Woods Geriatric Center. Panel discussion topics ranged from Urban Planning to the Intersection of Law, Religion, and Bioethics.

The Urban Planning discussion featured Dr. John Wegner, Director of Undergraduate Studies in Environmental Studies at Emory University. Dr. Wegner, claiming to be an

environmental ‘advocate’ instead of an activist, suggested an application of ecological landscape principles in developing the urban environment. The group questioned if urban planning was really possible, given the population explosion and if it would be put on hold in light of the events of September 11th. To answer the first part of the question, the panel suggested a new model—planning outside a central city core by using new telecommunications technology to disseminate populations from the central cities. This solution, however, like many, creates additional questions. How can we maintain a sense of community if we decentralize? What will be the impact on certain gender, racial, and class groups? In essence, how do we address issues of equality in urban planning? Our values are reflected in the ways we have planned our communities. Inequities are more than evident, and we must decide if urban planning causes social problems or if planning policies are simply a manifestation of pre-existing social problems. More importantly, how can scientists, bioethicists, and the like connect with and possibly offer solutions for these social issues when there is a barrier to communication and a gap between poverty and intellectuals?

Similarly, the discussion of the Intersection of Law, Religion, and Bioethics raised equally pressing ethical issues. Panelists included Dr. McGee, Michael Broyde, Associate Professor of Law and the Academic Director of the Emory Law and Religion Program, sociologist Timothy Lillie from the University of Akron, and Bobbi Patterson, Senior Lecturer in religion at Emory. The discussion first focused on explaining where society gets its values from in the context of making bioethics decisions. The American legal system tends to concentrate on personal rights and the boundary between individual rights and societal values. On the one hand, by drawing lines only in the face of harm to another, law establishes limitations before punishment. Religious values, on the other hand, revolve around an ideal that promotes divine behavior. Society gets its values from a conglomeration of the two. Thus, it becomes important to understand the interaction between law and religion in society, be it explicit or implied religious influence on secular law or secular law’s influence on religious conduct. Ideas then shifted to illustrate contemporary tension between law, religion, and bioethics. Dr. McGee presented three examples that he felt contribute to the collective sense that we do not know what we are doing—the Jack Kevorkian trials, clergy undereducated on important bioethics topics, and a lack of resources for judges that preside over bioethical cases. Each scenario would support a different approach in educational methods because each one involves decision-making based on inadequate information. Another discussion group on Transforming Science Education, composed of educators from Emory and Morehouse College, discussed specific strategies to effect such change.

After the first day of panel discussions and subsequent breakout sessions, Dr. Ursula Goodenough, professor of biology at Washington University, and author of The Sacred Depths of Nature, gave the second keynote address, focusing on the spiritual implications of scientific research. A molecular biologist and religionist, Dr. Goodenough shared some ideas concerning religious naturalism and mindfulness which are part of her next book. Arguing that objects, phenomena, and beings nature possess an

inherent spiritual worth, Dr. Goodenough formed connections between even the most basic science and a secular morality.

Another panel, Patient Rights: Spiritual and Ecological Perspectives, featured Emory-affiliated speakers. Kathy Kinlaw, Associate Director of the Emory University Center for Ethics and Director of the Center's Program in Health Science Ethics, addressed the debate over the right to minimal health care. Is there a minimal standard concerning the rights of patients to consent to medical treatment, to refuse treatment, or to demand a certain type of treatment? Gary Laderman, Associate Professor of Religion, provided a cultural history of patient's rights starting with the 1960's death awareness movements in which people struggled with questions of dignity and the treatment of the terminally ill. He commented that death, in modern society, is seen as a failure. How do we go about transforming death from a taboo topic, provoking images of fear and defeat, into a natural part of life? Tammie Quest, Assistant Professor at the Emory School of Medicine, detailed the provisions of the Patient Bill of Rights which include, but are not limited to, a right to information disclosure, a right to participation in treatment decisions, and a right to complaint and appeals. These opening thoughts served as a jumping-off point for discussion. Thoughts traveled from dispelling the medical myth that doctors are superhuman, especially in terms of death disclosure, to determining who, exactly, is the patient in the case of pregnant drug addicts. The group discussed decision-making capacity and the fine line between paternalism and listening to patient concerns. An important consideration includes how society questions the judgment of its devalued members, its alcoholics and HIV-infected individuals. The panel closed with a discussion of death and dignity as reflected by the changing views of society.

Perhaps the most seemingly incongruous session of the conference was the Disabilities and Ethical Dilemmas panel. It was led by Dr. Timothy Lillie from the University of Akron, Dr. John Banja, a clinical ethicist at the Emory University Center for Ethics, and Dr. Gregor Wolbring, research scientist at the University of Calgary Department of Biochemistry and Molecular Biology and an adjunct professor of Bioethics at the Department of Community Rehabilitation and Disability studies. Dr. Banja brought up patient's rights issues for neurologically disabled patients. What level of competence is required for informed consent? Dr. Lillie proposed two models of disability—a medical model that the body presents and a social model that depends on social environment. Dr. Wolbring justified the inclusion of disabilities in bioethical discussions. He commented on the double standard imposed on the disabled in genetic testing, genetic discrimination laws, and pre-selection for in vitro fertilization. The group speculated on who should bear the costs of disability—the government, society, or the patient, or some combination thereof. Would universal health coverage solve all problems? Questions were also raised regarding disability discrimination. Should a disability qualify as a reason not to hire someone if they may increase costs? If an 'invisible' disability has the potential to decrease job performance, is the employee obligated to tell the employer? These panels were followed by additional breakout sessions and a closing synthesis address by Dr. James Fowler, director of the Emory Center for Ethics.

While the conference may have ended, the discussion of bioethics continues. The ideas and questions developed here at Emory University travel with students and panelists back to their home institutions, as near as the Atlanta University Center and as far as the United Kingdom. For one weekend, the often-separate, but intrinsically linked disciplines of medicine and science were effectively brought together with a common goal—to learn from each other. The weekend was just the beginning. What happens now? Now, we change. We change our approach to science, the way we ask questions, and the way we do research. We have learned the importance of incorporating concerns for the diverse aspects of society into our thought processes and decisions. We have learned that bioethics extends beyond medicine and that we have more questions about these issues and fewer answers. The road ahead is long, and paved with trial and error as we formulate solutions to complex problems. We cannot afford to let technology race forward while education and interpersonal communication systems lag behind. We cannot afford to ignore the effects of medicine and technology on religion and ecology. As long as we insist on dividing societal and scientific realms, ethical dilemma will result from disparate value systems. Reconciliation and interdisciplinary dialogue may not be easy, but it's the best way to achieve meaningful progress.