InClass

A spotlight on faculty and their work

Standing at the Intersection

Ellen Wright Clayton's Genetics and Health Policy Center stands at the intersection of medicine and law, science and policy, past and future. By MICHAEL SIMS

Nowadays it seems that every news broadcast reports another step forward in genetics. Projects ranging from stem cell research to the Human Genome Project offer previously unimagined opportunities for healing some of the thousand natural shocks that flesh is heir to, but they also raise specters about employment discrimination, genetic profiling, and illicit bioengineering. Pundits respond by invoking scenes from the story of Frankenstein. They contrast the mad scientist's excitement as his creation first comes to life with his later fear as the monster runs amok. Understandably, many people worry that scientists—geneticists this time—are once again playing God and risking Frankensteinian consequences. Even commentators who resist the horror-movie imagery are likely to quote the dystopian visions of Orwell and Huxley in *1984* and *Brave New World*, or even Kurt Vonnegut's story "Harrison Bergeron," in which Americans in 2081 are required by the Handicapper General to be as alike as possible.

Ellen Wright Clayton wrestles with such issues all day long—not just advances in genetics, but also policymakers' response to them and how well or poorly the public understands them. In her new office in Vanderbilt's fledgling Genetics and Health Policy Center, which she launched and directs, the 50-year-old educator leans back in a chair behind a small conference table and asks, "What kind of society do we want to live in? How do we want to level the playing field? What kinds of accommodations do we want to make? These are the kinds of questions that drive my thinking."

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Such questions have been driving her for the last two decades. After a bachelor's degree at Duke and a master's from Stanford, she gradually merged her interests in law and medicine. Her J.D. from Yale in 1979 was followed six years later by an M.D. from Harvard. She joined the Vanderbilt faculty in 1988. Clayton is now professor of law, professor of pediatrics, and Rosalind E. Franklin Professor of Genetics and Health Policy. Clayton is also a senior fellow of the Institute for Public Policy Studies. Like her titles, her publications demonstrate the spectrum of her interests. Her books and articles address issues ranging from genetic screening of newborns to malpractice suits, from neonatal intensive care to the impact upon women of advances in medical technology. A single title for an article published in 1996 sums up Clayton's ongoing concerns: "Problems Posed by Genetics for Law and Ethics: American Policies."

"I've always been interested in social aspects of science and medicine," Clayton says simply. In the mid-1970s her graduate work in genetics at Stanford coincided with the formulation of guidelines for the use of recombinant DNA. Recombination is the formation of new gene arrangements. It can occur in two ways. Sometimes during cell division adjacent-paired chromosomes entangle and exchange corresponding

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{Suggested Reading}

1. Genetics and Public Health in the 21st Century: Using Genetic Information to Improve Health and Prevent Disease, Muin J. Khoury, Wylie Burke, Elizabeth Thomson, eds. (2000)

2. Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era, Mark A. Rothstein, ed., New Haven: Yale University Press (1997)

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segments. The change in genetic heritage resulting from this accidental "crossing over," as pioneer geneticist Thomas Hunt Morgan dubbed it, is a major force behind evolution. The second method is through laboratory manipulation; Clayton's graduate work was just in time for the launching of this whole new discipline. The field of genetic engineering is said to have begun in 1971, when the American geneticist Paul Berg created the first laboratory hybrid of DNA.

With the ramifications of these developments swirling around her, Clayton realized that she was actually more interested in policy than in pure science. She turned toward law school, where she wrote about genetic counseling and co-directed a year-long seminar on informed consent. Confessing that when she graduated from law school she wasn't sure just how to get into health policy, she adds, "I decided that it might be efficient—which shows you why I'm not an economist—to go to medical school and learn more about it. And I really went to medical school sort of with this idea that I was going to wind up at this intersection."

Today, surrounded by the unfinished offices that embody the intersection of her interests, Clayton gestures around. "My vision is to sort of pull together some of the many strengths of this university and this city and then create a space where other faculty and other students can come in and explore some of these issues."

Clayton sees herself primarily as an educator, interested in policy but also in education and public outreach. "I'm almost a constitutive teacher," she adds, and explains with a smile, "*Constitutive* is a genetics term for a gene that's always turned on." She teaches one or two classes per year, usually including an interdisciplinary course in family law and bioethics and law. She directs a new genetics course and teaches in the Medical School's Ecology of Medicine course. Every week also finds her working as a preceptor in the hospital wards or in the clinic. Frequently, she guest lectures in other schools within Vanderbilt, including divinity, business and even engineering.

Besides teaching classes, Clayton currently pursues a number of projects. A law student from Germany is teaming with her on drug development and testing in pediatrics. A pediatric colleague is writing about HIV vaccine trials among adolescents; Clayton hopes to link him with the German law student. Officials in the U.S. Episcopal Church approached Clayton with a desire to better understand issues about genetics and medical ethics, to help them formulate responsible church guidelines based upon accurate information and predictions.

Science alone is never enough because the public at large needs not raw information but a translation into comprehensible terms that make it relevant to ordinary lives and immediate issues. Of course, the first goal of responsible policymaking is accurate data. "My interest is not only in getting the science right," Clayton explains, "but in really taking a hard-nosed look at the way the scientific information is used in society—with the idea being to try to figure it out in a way that we can optimize the way it's used."

Clayton insists on taking an equally hard-nosed look at how the information is gathered in the first place. Another current project embodies her approach. She describes it as "the so-called haplotype map project, which hasn't even been formally announced yet." A haplotype is any particular set of markers on a certain region of a chromosome. A good example would be alleles, alternative forms of a gene, which cause different expressions of the same trait, such as eye color, among members of a population who share the same genetic heritage. "The purpose of the haplotype map is to make it easier and less expensive to find new genes. This is a fourth-generation genetic map, which is going to begin to try to lay out some of the patterns of genetic diversity among people from different parts of the world."

Clayton predicts that, as usual, people with various political agendas—or people simply ignorant of the complexities involved—will claim that any genuine biological differences between groups are more influential than is really the case. Such misunderstanding can begin at an early stage. "The science is constrained," Clayton explains, "by the fact that these social categories don't completely describe what we need to be looking at." One of the tasks of science is to ask new questions, and frequently the job involves formulating new concepts. Like other tools, concepts don't grasp every fragment of information equally well. This limitation is especially true among issues concerning radioactive topics such as gender and race.

Another issue that Clayton frequently receives questions about is cloning. Confusion about this procedure results partially from the distinction between reproductive and therapeutic cloning. Reproductive cloning involves the asexual production of an individual that is genetically identical to its "parent." The most famous example so far is the creation of the sheep Dolly in the late 1990s by the Scottish geneticist Ian Wilmut and his colleagues at the Roslin Institute in Edinburgh. They cloned Dolly by removing the nucleus from an ovum in the udder of one sheep and fusing it with a somatic (non-reproducing) cell from another sheep, then transplanting this pre-embryo into the womb of a third sheep. The great fear, of course, is that eventually this procedure, called "somatic cell nuclear transplant," will be employed to clone human beings. Clayton says flatly, "I think that the first issue about reproductive cloning—certainly in the United States—is simply that the overwhelming majority of people think it's a bad idea."

Therapeutic cloning, in contrast, involves the removal of the pre-embryo to produce tissue or an entire organ for transplantation back into the patient who supplied the initial DNA. It, too, faces opposition because the best cells to use are embryonic stem cells. A stem cell is one that can generate various types of cells, and the most versatile stem cells, not surprisingly, are found in embryos. The moral and legal question is how and when human embryos may be used in such treatments. Despite the controversies involved, many scientists consider therapeutic cloning the inevitable next step after organ transplantation—which, although once similarly resisted, has become an accepted and common procedure. "The benefit of therapeutic cloning," Clayton explains, "is to create matched tissues for treatment." It would provide naturally customized organs for donors who could then avoid the health risks of long waiting lists. Therapeutic cloning would also help prevent the body from rejecting a transplanted organ. If the organ were cloned from the

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patient's own DNA, her immune system would have no reason to reject it.

Clayton shrugs. "But do I think that we're anywhere near therapeutic cloning in humans? No." She points out that all these goals are still in their infancy, and that scientists aren't even sure if stem cell research—assuming that Congress doesn't ban it in the U.S. entirely—will live up to expectations. "It seems to me that, unless you're driven entirely by the notion that you can't destroy an embryo *ever*, then *if* it turns out to be effective, we really do have to think about what to do about somatic cell nuclear transplant for therapeutic purposes."

One misconception that Clayton sees growing in force among the public, thanks to extensive (if not always careful) media coverage of genetics, is "the idea that it's creating among people that if you just know your genes, you know what's going to happen to you. Now that's simply untrue," she insists of this different sort of Frankensteinian vision. "I'm an anti-determinist. I certainly don't think Genes-R-Us. So I am much more open to the notion that the genes give us a range of opportunities, and we have to figure out where we're going to be within that range."

Ellen Wright Clayton is used to offering informed opinions. She leans back in her chair and quietly declares a position based upon experience that goes back to the early days of this challenging and still young discipline: "I'm not even a philosophical anti-determinist. I just think the biology tells us that environment makes a huge difference." ▼

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guide, *LaRousse Gastronimique,* this one in its original French language.

Celebrities, both real and fictional, take turns in the kitchen: *Peter Rabbit's Natural Food Cook Book* (with Beatrice Potter illustrations); *Dining With Sherlock Holmes*; *The Pooh Cook Book*; *Hotel Bemelmans* by *Madeleine* author and illustrator Ludwig Bemelmans; and an impressively bound and photographed volume of recipes from famous restaurants around the world compiled and published in 1965 in *A Treasury of Great Recipes* by Mary and Vincent Price.

Budding young chefs are not forsaken: There is a whimsical children's book—*Mud Pies and Other Recipes*, and *The Teen-Age Cook Book* with recipes for a Sunday dinner they might prepare featuring roast mutton. Some of the titles are not quite so appealing: *The Mayo Clinic Renal Diet Cook Book*, *The Prudent Diet*, *The I Hate To Cook Book,* and *The School Lunch Cook Book*.

But certainly the collection as a whole will whet the appetites of cooks and gourmands and would prove invaluable in undertaking Brillat-Savarin's final aphorism: "To invite people to dine with us is to make ourselves responsible for their well-being as long as they are under our roofs." ▼

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rience and election outcome with insight and humor, noting that he is working to mend political fences in Tennessee and staying involved in national politics and issues. Again, the students put tough questions to the Vice President, and he pulled no punches. It was a great finish to the course.

I had begun this class with an idea, helped along by John Geer's tutoring in the art of the classroom presentation, University politics, and the challenge of grading student's papers. It was thrilling to be back on the campus and gratifying to teach with one of Vanderbilt's finest professors. But I especially enjoyed getting to know these students and watching them dive into a new subject with great interest.

Early in the course one of our best students told me of her new-found passion for political science. This young woman works as a waitress during every school break throughout the year to help pay Vanderbilt's hefty tuition. She thought this class was worth her hard work, and that was all the reward I needed in my return to the University. And, yes, she got an A in the course.

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cities are as segregated as the deep South ever was. However, people who say we haven't made progress should try to imagine the South of the 1950s. The fact is that we had a system of apartheid almost as rigid as that in South Africa. Water fountains, restrooms, waiting rooms at bus stations and movie theaters were just as segregated as were our schools. When it came to things like hotels and restaurants, most were simply not available for African Americans. While young African American students today have hurdles to overcome that are greater than their white counterparts, the fact is that the hurdles facing young African Americans in the segregated South were so high that only a very few could overcome them, and they were usually people with extraordinary talent, like a Leontyne Price or a Hank Aaron.

As for the situation at Vanderbilt today, my biggest disappointment, and one that is shared by a large percentage of the faculty, is the difficulty we face in significantly increasing our African American population here. In that regard, the position of people who are opposed to affirmative action seems difficult to defend. We kept people in chains for 200 years, then put them in a segregated society not that much better than slavery, and then grudgingly tore that down only two generations ago. And now we don't want to give any special provisions to try to help members of that group catch up. The analogy that has often been used, but which is true, would be that of a race in which one runner has his legs tied together while the other runs halfway around the track. At that point, the ropes are untied, and from then on it is regarded as a fair race. That just doesn't hold water.

Fortunately, the current leadership at the University is committed to diversity, and rightfully so. They know that Vanderbilt's goal of being in the top tier of American universities will never be realized until our student body and our faculty begin to mirror the make-up of the nation as a whole. Then again, they also know that developing a more integrated, inclusive university is simply the right thing to do. ▼