Essay by Lori Andrews

Shortly after the announcement of the creation of Dolly the cloned sheep, a remarkable group came together at the Illinois Institute of Technology in Chicago. They included Scottish biologist Keith Campbell, Dolly’s creator; British in vitro fertilization pioneer Robert Edwards, who created the world’s first test tube baby; Mary Beth Whitehead, the surrogate mother who fought for custody of the child she contracted to bear; and Arthur Caplan, the charismatic University of Pennsylvania bioethicist. At that meeting, physicist Richard Seed shocked the world by announcing that he was planning to clone a human being.

Seven years have passed since that meeting and, so far, Seed has not accomplished his goal. But the ideas planted at that gathering have flowered into a major bioethics initiative in Illinois. During the past year, the U.S. Congress granted more than $1 million to the Institute on Biotechnology and the Human Future at the Illinois Institute of Technology to advise the government, the public, businesses and professional organizations about the risks and benefits of biotechnology.

It’s no surprise that Illinois is the center of bioethics dilemmas. Policy decisions about cutting-edge technologies are encountered every day in the Land of Lincoln, with its more than 300 biotech and pharmaceutical companies, 224 hospitals and 23 cutting-edge infertility clinics — not to mention the headquarters of national organizations such as the American Medical Association, the American Hospital Association, the American College of Surgeons, the American Academy of Pediatrics, the College of American Pathologists and the American Bar Association.

Controversies abound. At the Reproductive and Genetics Institute in Chicago, Yuri Verlinsky undertakes preimplantation genetic screening on human embryos so that couples can choose to implant embryos without the chromosomal anomaly of Down Syndrome or the genetic mutation predisposing the child to early onset Alzheimer’s disease. Some people welcome this technology as a new form of preventive medicine, others criticize it as a private approach to eugenics.

At Northwestern Medical Center, a massive genetic research project known as NUgene was created using tissue from patients, with their consent. Some people see this as a boon to the identification of genetic mutations that cause disease. Others worry that their genes may be patented, leading to high prices for genetic tests and bans on other researchers’ use of patented genes. Certain genes that predispose people to breast cancer were patented by the biotech company Myriad. Now the company forbids doctors from looking at those genes in their patients’ blood. Instead, the doctors must send the blood to a Myriad-related lab, and Myriad can charge whatever it wants for the test. Current rate: $2,975. Before Myriad asserted its patent rights, the test was available at a much lower price.

After a car accident on an Illinois highway, a young doctor was called in to collect sperm from the dead man so that his widow could bear his child. Some view postmortem parenting as expanding reproductive choice. Others argue that procreation without the man’s advance permission is morally akin to rape.

Meanwhile, in hospitals across the state, doctors and family members are dealing with more commonplace, but equally difficult, decisions pertaining to the end of life. When should medical treatment for a comatose individual be terminated as futile? What role should the family play in the decisions? What if there are disputes among relatives about what should be done?

Illinois courts and the legislature have spent a considerable amount of time dealing with the profound social and legal issues surrounding the end of life. In 1988, 8-month-old Sammy Linares swallowed a balloon and suffocated. He fell into a coma, in what seemed to be a persistent vegetative state with no apparent hope for recovery. The parents begged the Chicago hospital to disconnect the boy’s respirator, but the hospital refused. Finally, when Sammy was 16 months old, and still in a coma, his father warned the hospital staff off with a gun and disconnected the respirator. Although a grand jury threw out the murder charge against him, he was convicted of assault with a deadly weapon.

Since that time, Illinois has clarified its rules about termination of treatment. In Illinois, a person can use a living will to indicate in advance his or her wishes about life-sustaining treatment. Or that person can appoint a surrogate health decision maker, under the Illinois Power of Attorney Act. If a patient is incapable of making a decision and has given no advance indication of what he or she would want, the Health Care Surrogate Act describes how to determine which person close to the terminally ill individual is empowered to make the decision to withdraw treatment.

A mainstay of bioethics inquiry for nearly four decades, end-of-life decisions are being pushed aside by new questions at the opposite end of life’s spectrum. Amidst a biotechnology revolution that makes the industrial revolution look mild, many profound new ethical issues deal with the beginnings of life. It’s now possible for a child to have six or more parents: an egg donor, sperm donor, surrogate mother and her husband, and the rearing couple.

In the United States alone, an increasing number of children are created each year with the aid of fertility technology, at a cost of $4 billion. Fetuses can be tested before birth — even before implantation — for more than 500 genetic mutations, ranging from serious diseases such as Tay-Sachs to characteristics such as perfect musical pitch.

Americans increasingly approach procreation with a shopping-list mentality. Each year, nearly 100,000 births occur after donor insemination or with egg donation, with many people choosing their future babies according to the hair color, hobbies, SAT scores, height (for men) and weight (for women) of the donors. An ad in a Stanford University newspaper offered $100,000 for an egg donor with “proven college-level athletic ability.” People who can’t get enough
tabloid coverage of royals can pay $4,000 for the sperm of a man who traces his lineage to European royalty and several Catholic saints. He advertises on a “royal and biblical gene” Web site that pays $500 to doctors for referrals.

Some parents abort girl fetuses because they want a boy. In one study, 12 percent of parents said they would abort a fetus with a genetic predisposition to obesity. In California, a court suggested that a disabled child could sue her parents for not aborting her. Imagine the lawsuits! A daughter might sue her folks for not making her prettier by paying for a “better” egg donor — or for not using genetic enhancement to make her smarter.

As technology evolves, parents-to-be will have even more control over the traits of their offspring. Scientists have already put human cancer genes in mice and firefly genes in tobacco plants, causing them to glow in the dark. Now genetic engineering is being proposed for human embryos. Where might that lead? In a Louis Harris poll sponsored by the March of Dimes, 43 percent of respondents said they approve of changing the makeup of human cells to improve babies’ physical characteristics; 42 percent approve of upgrading children intellectually. Another survey found that more than a third of people would like to genetically control their child’s sexual preference.

Some scientists suggest modifying people with the gene to photosynthesize so that we could get our energy from the sun like plants and not waste money or time getting food. Law review articles already are raising questions about how to treat these new creations. If an individual had half animal and half human genes, would he be protected by the U.S. Constitution? When I asked my law students that question, one replied, “If it walks like a man, quacks like a man, and photosynthesizes like a man, it’s a man.”

The very boundaries of what is human are being changed by genetic technology. Yet hardly anyone in the public or the legislatures is paying attention. We might notice if a totalitarian government decided to inoculate all its citizens with the photosynthesis gene. But the change, the designing of children, is occurring much more subtly as a result of individual choices through an open market.

Thousands of couples turn to the Internet to find genetic parents for their future children. They view pictures of sperm and egg donors, listen to tapes of their voices and review pages of descriptions of their physical features, their hobbies, their SAT scores, their philosophies of life. At the Ronsanges.com Web site, couples bid on the eggs of attractive models. At the Repository for Germinal Choice, they purchased sperm from Nobel laureates. Can purchasing single gene “upgrades” be far behind?

How are we, as a society, going to judge such desires? Should certain genetic manipulations be allowed and others not? Should parents be able to buy height-enhancing genes for their embryos? Will that be viewed more like cheating in sports or more like signing your child up for private tennis lessons? Is giving a child a gene protective against a deadly disease appropriate but manipulating genes for cosmetic purposes not? Should parents be permitted to give their infants genes for traits that humans never had before, like the running speed of a cheetah? And if the designer babies did not turn out the way the parents had planned, should lemon laws for children allow them to get their money back?

Creating a baby is beginning to resemble buying a car with consumer choices about which features and extras to request. Yet children don’t come with the same guarantees as do cars or toasters. The child of an attractive model could be downright homely. And Nobel Prizes tend to be awarded to people in the same laboratories rather than in the same families. William Shockley, a Nobel laureate sperm donor, once said that his own children were a “regrettable regression to the mean.”

How will parents feel if they pay for “smart” sperm, and E=mc² isn’t the first thing out of their child’s mouth? Already, one couple sued a sperm bank when the babies weren’t as handsome as they had wanted.

Reproductive and genetic technologies are developing with very little oversight in this country. Part of the freedom from regulation is a result of constitutional protection of reproductive choices. And part is from a legislative paralysis wherein lawmakers are afraid to act because, unlike many other policy areas, everyone...
has an opinion about how the next generation should come into the world. Any regulation is bound to offend someone.

More important, though, the sociaetl debate about abortion has prevented any federal research funds from being used for procedures involving embryos. One consequence of the lack of federal funds is a dearth of outcome studies on the women and children involved in reproductive technologies. Another consequence is that experimental procedures are introduced into clinical practices without sufficient protections for the subject of these experiments. In other areas of medicine, research is initially funded by the federal government and, by federal regulation, must be reviewed in advance by a neutral committee, the Institutional Review Board, before it can be tried in humans. Since reproductive technologies have been held hostage to the abortion debate, they have not received federal funds. Researchers can still submit their plans to hospital and university institutional review boards, but they usually do not. In fact, according to in vitro fertilization doctor Mark Sauer, review board scrutiny of reproductive technology proposals is so rare as to be “remarkable.”

Unlike new drugs and new medical equipment that are regulated by the federal Food and Drug Administration, no similar review of innovative reproductive technology procedures is required. Reproductive technologies also differ from other medical procedures because they are rarely covered by health insurance; only 15 states’ laws, including that of Illinois, mandate some form of infertility coverage. This means that clinics are in a fierce competition for wealthy patients. To boost success rates, some clinics report as “pregnancies” small hormonal shifts in a woman’s body that show that an embryo had briefly implanted — and then been reabsorbed by her body. Others implant as many as 10 embryos or use infertility drugs indiscriminately to increase the number of babies the clinic creates, even though this increases the risk to the woman and the fetuses.

Lack of insurance coverage also means that reproductive technology lacks an additional aspect of quality assurance. For other types of health services, health insurers, through managed care outcome studies and evaluation of services, have required certain proof of efficacy before medical services are reimbursed. But because infertility and genetic services are often paid for out-of-pocket, there is less oversight of the procedures undergone by couples and their babies-to-be.

In the United States, the assisted reproductive technology industry is growing to serve an estimated one in six American couples who are infertile and the many more who want to control the genetic traits of their children. More babies are born through reproductive technologies than are available for adoption. One of the most striking things about this comparison is that every state has an elaborate regulatory mechanism in place for adoption while only a few states have enacted legislation to comprehensively address assisted reproductive technologies. Illinois is not one of them.

Yet reproductive and genetic technologies have risks that we should protect people against. They also assault social values in other ways. Germline genetic intervention on human embryos may increase cancer risks, sterility or other problems in the next generation. Proponents of genetic engineering of humans suggest that it is no different than selective breeding of animals. But geneticist Jon Gordon points out there are enormous differences when only a single gene is being introduced in a complex organism. Gordon notes that, unlike selective breeding, where numerous favorable genes are passed on at the same time, gene transfer selects only one gene and tries to improve the trait in isolation. Gordon notes that, in animals, this single-gene approach has, “despite more than 10 years of effort, failed to yield even one unequivocal success.” Instead, it has produced disastrous results.

When a gene shown to induce muscle hypertrophy in mice was inserted into a calf, the animal did exhibit the desired trait initially, but later exhibited muscle deterioration. The animal had to be shot.

In a separate experiment, researchers genetically enhanced the wings of flies to be 300 percent stronger than average. Instead of creating a superfly, these flies couldn’t even get off the ground because they were no longer able to move their wings fast enough.

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Making laws for making babies

In a field with no clear social or ethical rules, courts are asked to decide subtle and far-reaching issues, such as what obligations society owes to human embryos and whether the state legislature can ban the use of certain new technologies.

Last month, a judge in Cook County considered a lawsuit by a couple against an infertility clinic that the couple says wrongfully destroyed their embryo. The judge held that the embryo could be considered a "human being" for purposes of a wrongful death suit so that the couple would have a means of suing the clinic for not taking proper care of the embryo. The decision immediately sent shock waves through the Illinois in vitro fertilization community.

Not all embryos turn into live born children. Only 30 percent of embryos fertilized naturally inside a woman's body turn into live births. But if an embryo in a clinic did not develop into a child, and the embryo was considered a person, could the in vitro fertilization doctor be charged with murder?

And what happens when the couple and the clinic have the same goals, but the legislature wants to restrict their choices? Shortly after the 1976 birth of Louise Brown, the first test tube baby, Illinois lawmakers passed an unusual law to deter doctors from doing in vitro fertilization. The law said that any physician who fertilized an egg in vitro had custody of the resulting embryo and would be subject to an 1877 child abuse law.

Doctors in Illinois were afraid to use the procedure. They knew what it meant to provide an existing child with the food, clothing and shelter necessary to avoid a finding of abuse, but what did it mean in terms of an eight-cell embryo? Could a prosecutor indict a doctor each time an embryo failed to develop into a child — on the grounds that the doctor should have "fed" it a more "nutritious" petri dish mixture? Would the doctor be guilty of homicide if he or she discarded an embryo that was not dividing properly?

Another land mine was that the law granted custody to the doctor but never arranged for the parents to regain custody. If such a law had been in effect in England, Lesley and John Brown would have had no legal claim to Louise — she would have belonged to Robert Edwards and Patrick Steptoe, the doctors facilitating her birth.

There was no question that a married couple has a right to determine whether and when to bear a child through intercourse. But did a couple also have the right to decide how they would like to bear a child? Attorneys for the American Civil Liberties Union (Colleen Connell, Lois Lipton and Frances Krasnow) and I challenged this law in Litch l v. Hartigan in 1990. "While the legislature apparently views in vitro fertilization as a crime," we wrote in our brief, "to many childless couples it is seen as a possible miracle... Procreation is universally recognized by every culture and religion as a fundamental element of the institution of marriage. For many married couples it is the essence of family. The desire to produce one's own offspring is, for most couples, as primary as the need to eat or sleep."

We argued that because the Illinois law was interfering with that decision, the law should be declared unconstitutional. In response, the Illinois legislature changed the law to ban embryo research — except for in vitro fertilization. Once again, we were back in court, saying the statute violated reproductive freedom.

Federal Judge Ann Williams agreed with us and ruled the law, which predated stem cell technology, unconstitutional. Her opinion read: "It takes no great leap of logic to see that with the cluster of constitutionally protected choices that includes the right to have access to contraceptives, there must be included within that cluster the right to submit to a medical procedure that may bring about, rather than prevent, pregnancy."

Eventually, in vitro fertilization, in which a woman's eggs are fertilized with a man's sperm, gained fairly widespread acceptance. There is still controversy, though, about various adjuncts to in vitro fertilization. Should embryos be split in half to create identical twins and potentially increase the couple's chance of a successful pregnancy? Should women be allowed to use donor eggs and hormones to have children once they are past menopause? What sort of genetic screening, if any, should be allowed on preimplantation embryos? What should be done with frozen embryos a couple no longer wants? Should people be cloned? There are limits to reproductive liberty. People's constitutional right to make reproductive decisions does not extend to the right to use certain dangerous technologies. For example, reproductive liberty arguably does not include a right to clone human beings. It is just too dangerous. In animal cloning, one-third of the animals die shortly before or shortly after birth.

Even if reproductive cloning posed no physical risks, the emotional impact on the offspring could be devastating. If a cloned person's genetic progenitor is a famous musician or athlete, parents may exact an improper amount of coercion to get the child to develop those talents. True, the same thing may happen now — to a lesser degree — but the cloning scenario is more problematic. A parent might force a naturally conceived child to practice cello hours on end, but will probably give up eventually if the child seems uninterested or tone deaf. More fervent attempts to develop the child's musical ability will occur if the parents chose (or even paid for) nucleic material from Yo-Yo Ma. And pity the poor child who is the clone of Michael Jordan. If he breaks his kneecap at age 10, will his parents consider him worthless? Will he consider himself a failure? And what if the original Michael Jordan dies of an inheritable genetic disorder? His clones might become unemployable or uninsurable due to the forewarning of a potential problem in their genes.

Ours is going to be the generation that decides: Will we live among cloned human beings? Watch sports played by genetically enhanced athletes? Use prenatal screening as admission standards for birth? As we address these issues, we need to be mindful of the impact of biotechnology on the people who use them, the resulting children and on society as a whole.

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In another study, researchers inserted an extra NR2B gene linked to long-term memory and increased cognitive and mental abilities into mouse embryos. The resulting animals (called “Doogie Howser” mice) seemed to move more quickly through mazes than the mice that had not been altered. Immediately, the question arose about whether such interventions should be undertaken on humans. Yet subsequent research, by other scientists, learned the genetic intervention had a downside. The Doogie Howser mice were more susceptible to long-term pain. The results of such studies raise many cautions against attempting genetic engineering of humans.

Scientific developments present novel challenges for policymakers, courts, private industry, the public and the media. Already some consumers report that they were not told about the physical risks of fertility drugs and multiple birth pregnancies, or that reproductive technology may require tens of thousands of dollars and years to achieve a live birth. Other people report that employers, insurers, schools and courts already have discriminated against them on the basis of their genetic makeup. Employers and insurers have a financial incentive to reject healthy applicants with genetic mutations predisposing them to diseases (such as certain cancers) that might require expensive health care or might reduce productivity in future years.

The possibility of having a widespread societal debate in the United States about biotech’s scientific and medical risks and benefits to individuals, cultural values and political institutions has been hampered by extreme divisiveness on the issue of abortion. But society must immediately find answers to a number of issues raised by biotechnology in a manner that balances private rights and public good, including: How can the safety of new biotechnologies be assured? Should parents be allowed to genetically engineer and enhance their child with desired traits, creating “designer babies”? Do people who learn they have genetic irregularities have a moral or legal duty to report them to family members who may also have the inherited mutation? Should the government allow or prohibit technologies that would significantly alter the human race?

To foster discussion and examination of such questions, Congress turned to the Institute on Biotechnology and the Human Future, directed by bioethicist Nigel M. de S. Cameron at the Illinois Institute of Technology. The institute’s board, which I chair, serves as a think-tank that is reflective of the population — some board members are anti-abortion, others favor abortion rights; some are politically conservative, others liberal; some are secular, others religiously conservative. The board is a coalition of pre- eminent and socially and religiously diverse academics, policy experts, lawyers, scientists, physicians, activists and ethicists who are dedicated to setting aside their differences on the abortion debate to work toward guaranteeing that biotechnology sustains, rather than weakens, human health and social values.

In my own work, I study the impact of new medical technologies on individuals, families, communities, social institutions and society at large and then suggest social policies to deal with the benefits and risks of those technologies. I view my work in law as akin to writing science fiction. The challenge is to try to determine what society would look like if we choose one path as opposed to another. I often think of Dame Mary Warnock’s admonition when her British committee was making recommendations about reproductive technologies: that we try to create a society that we can praise and admire, even if in individual detail we may wish it were different.

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For additional resources on this subject, see Illinois Issues’ Web site http://illinoisissues.uis.edu.