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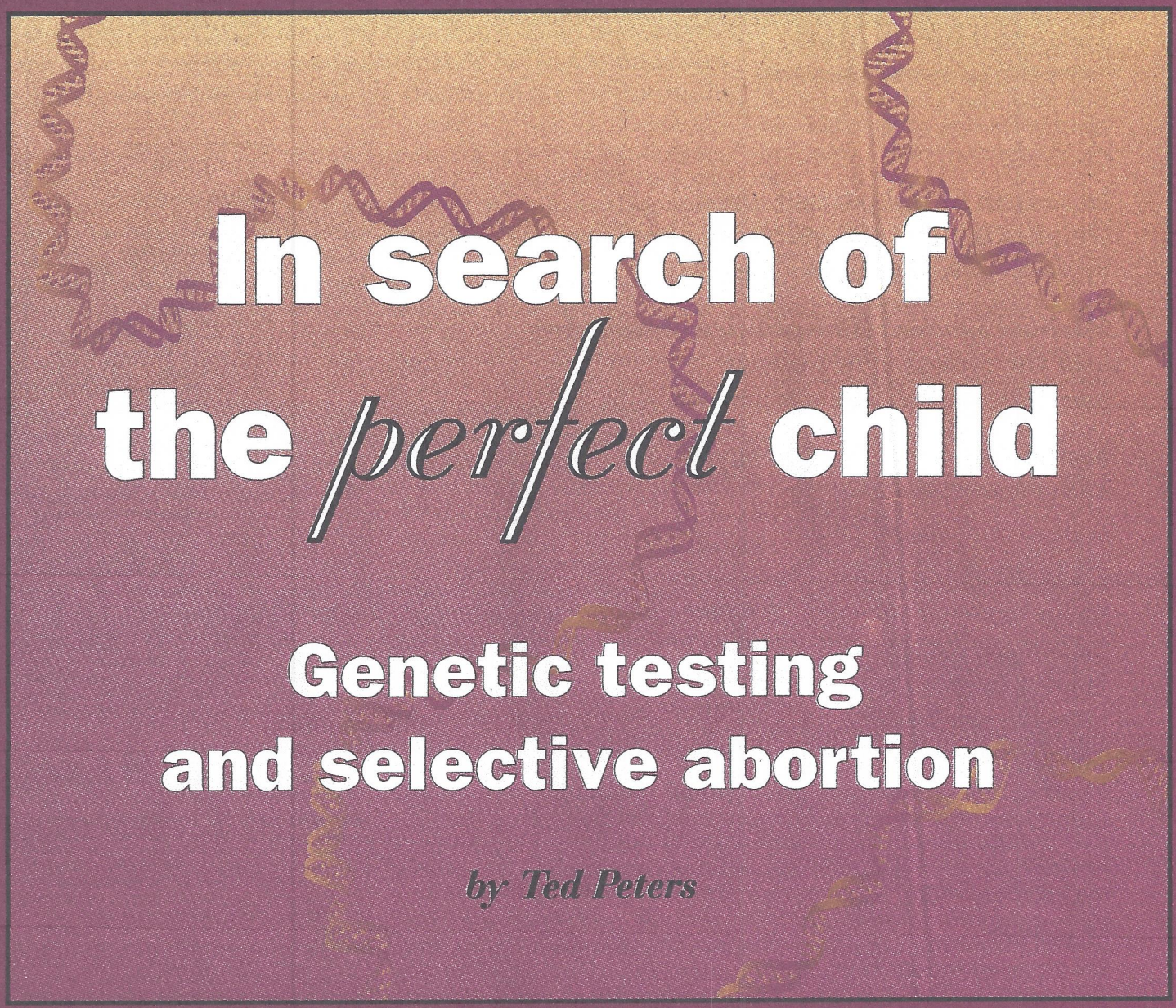

In search of the *perfect* child

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In search of the perfect child: Genetic testing and selective abortion

by Ted Peters

THE TRIUMPHS of genetic research include the discovery of disease-related genes. The gene for cystic fibrosis, for example, has been found on chromosome 7. Huntington's chorea was discovered lurking on the end of chromosome 4. Inherited breast cancer was traced to chromosome 17, early-onset Alzheimer's disease to chromosome 14 and colon cancer to chromosome 2. Disposition to muscular dystrophy, sickle-cell anemia and 5,000 or more other diseases is being tracked to genetic origins. The search goes on as well for the DNA switches that turn such genes on and off, and for genetic therapies that will turn the bad genes off and keep the good genes on. Such discoveries could improve medical diagnosis, prevention and therapy, thus advancing the quality of health for everyone.

Couples are likely to experience increased social pressure to abort less-than-perfect fetuses.

Yet this apparent good news comes as bad news to those born with genetic susceptibilities to disease, because medical care is funded by private insurance companies and medical insurance is tied to employment. An identifiable genetic predisposition to disease counts as an existing condition, and insurance companies are beginning to deny coverage to people with existing conditions. As new techniques for prevention and therapy become available, the very people who could benefit may be denied access to them.

Paul Billings, a genetics researcher and ethicist at Stanford University Medical School, has collected anecdotal evidence of genetic discrimination. Testifying before Congress, Billings told of a woman who, during a routine physical, spoke to her physician about the possibility of her mother having Huntington's disease. Later, when the woman applied for life insurance, her medical records were reviewed and she lost all her insurance.

In another case, a 14-month-old girl was diagnosed with phenylketonuria through a newborn screening program. A low phenylalanine diet was prescribed, and her parents followed the diet rules. The child has grown up to be a normal and healthy person. Her health care at birth was covered by a group insurance policy associated with her father's employment, but when he changed jobs the new carrier declared her ineligible for coverage. Once a genetic predisposition for an expensive disease becomes part of one's medical record, insurance carriers and employers connected to them find it in their best financial interest to minimize or deny health coverage.

In a report by the Committee on Government Operations, U.S. Representative John Conyers (D., Mich.) responded to Billings and others: "Like discrimination based on race, genetic discrimination is wrong because it is based on hereditary characteristics we are powerless to change. The fear in the minds of many people is that genetic information will be used to identify those with 'weak' or 'inferior' genes, who will then be treated as a 'biological underclass.'"

Until recently, the federal government has been slow to respond to testimonies made on behalf of the next generation. In an effort to draw attention to the issue, researchers in the Working Group on Ethical, Legal, and Social Implications of the Human Genome Project at the National Institutes of Health and the Department of Energy created a task force that included geneticists, ethicists and representatives from the insurance industry. The central message of their 1993 report is that information about past, present or future health status—especially health status due to genetic predispositions—should not be used to deny health care coverage or services to anyone.

Some officials are listening. The Kassebaum-Kennedy health insurance reform bill passed in August prohibits categorizing a genetic predisposition as a disqualifying precondition.

ANOTHER CHANGE occurred when U.S. Marines John Mayfield and Joseph Vlacovsky refused to allow their DNA to be deposited in a Pentagon data bank. The two men were court-martialed, but later the Pentagon dropped its original plan to keep DNA information for 75 years. Fearing that genetic information could be used to discriminate, it now restricts the use of DNA to the identification of human remains on the battlefield. Donors may request destruction of their gene samples when they leave Defense Department service.

Late last year the Genetic Privacy Act was introduced in Congress as well as six state legislatures. The proposal governs collection, analysis, storage and use of DNA samples and the genetic information obtained from them. The

act would require explicit authorization to collect DNA samples for genetic analysis and limit the use of information gained from them. The aim is to protect individual privacy by giving the individual the right to authorize who may have access to his or her genetic information.

This is a good start, but it is not enough. Laws to protect genetic privacy appeal to our sense of autonomy, to our desire to take control of what appears to be our own possession, our genome. But privacy protection in itself will not eliminate the threat of genetic discrimination. First of all, it probably will not work. Genetic information as well as medical records are computerized. Computers are linked. In the world of the Internet, someone who wants to penetrate the system will eventually find a way to do so. Any attempt to maintain control over genetic information is likely to fail.

Second, privacy regarding one's genome is undesirable. Knowledge of one's genome could improve preventive health care. The more our physicians know about our genetic predispositions the more they can head off difficulties before they arise. Rather than privacy, what we want is the use of genetic information that does not discriminate against people because of their genetic makeup.

Genetic knowledge can help us treat or prevent some diseases, but it can also be the basis for discrimination.

A few years ago my 23-year-old godson Matthew was rushed to the hospital for emergency surgery. He was diagnosed with familial polyposis, a colon cancer in an advanced stage. In a heroic effort, the surgeon's team managed to remove all malignancy. Afterward the surgeon asked the parents if there were any cases of colon cancer in Matthew's family. "We don't know," the parents answered, explaining that Matthew had been adopted as an infant and his records were closed.

"Well," said the doctor, "this kind of cancer is genetic. Had we known that Matthew had a predisposition, we could have monitored him from age ten and removed precancerous polyps. He would never have come to this crisis situation." This case shows the value of computerized and sharable genomic information.

At some point in the future a simple blood test will reveal each of our individual genomes, and we may be able to use this knowledge to great benefit. Laws promoting genetic information without discrimination will contribute to better health care rather than deny it.

A number of states have laws allowing genetic information to be secured from birth parents and made available to adopting parents. In this way, one can learn the frequency of a disorder in a family but not the identity of the family. As genetic testing becomes more sophisticated, DNA tests will provide the same information.

But if adopting parents view adoptable children as commodities to be consumed, such genetic testing could inadvertently lead to discrimination. If the child tests positively for a genetic defect, the adopting parents may think of the child as defective and refuse to adopt him or her. They may be caught up in the "perfect-child syndrome" and want nothing less than a perfectly healthy child. Or they may cancel the adoption because they fear that they'll lose their family health care insurance and become stuck with unpayable medical bills. The first problem is cultural or ethical, the second economic.

CAN WE FORECAST a connection between genetic discrimination and selective abortion? Yes. A couple in Louisiana had a child with cystic fibrosis, a genetic disorder leading to chronic lung infections and excruciating discomfort. When the wife became pregnant with the second child, a prenatal genetic test revealed that the fetus carried the mutant gene for cystic fibrosis. The couple's health maintenance organization demanded that they abort. If they refused to abort, the HMO would withdraw coverage from both the newborn and the first child. Only when the couple threatened to sue did the HMO back down and grant coverage for the second child.

With the advance of prenatal genetic testing, both parents and insurance carriers can find out whether a child may be prone to having a debilitating and expensive disease. It is not unrealistic to imagine the insurance industry publishing a list of disqualifying genetic predispositions. If one of the predispositions were found in a fetus, the industry would mandate an abortion under penalty of loss of coverage. This would outrage pro-life parents, and even pro-choice parents would find this financial pressure to be the equivalent of a compromise on choice.

We are moving step-by-step toward this selective abortion scenario. In addition to feeling pressure from the privately funded insurance industry, parents themselves will likely develop criteria for deciding which fetuses will be brought to term and which will be aborted. Genetic criteria will play a major role. Prenatal testing to identify disease-related genes will become routine, and tests for hundreds of deleterious genes may become part of the prenatal arsenal. Parents wanting what they believe to be a perfectly healthy child may abort repeatedly at each hint of a genetic disorder. Choice and selection will enter the enterprise of baby making at a magnitude unimaginable in previous history.

Most families will confront the issue when they find themselves in a clinic office talking with a genetic counselor. Although a genetic analysis of heritable family traits can help immensely in planning for future children, talking with a genetic counselor too often begins when a pregnancy is already in progress. The task of the genetic counselor is to provide information regarding the degree of risk that a given child

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might be born with a genetic disorder, and to impart this information objectively, impartially and confidentially (when possible) so that the autonomy of the parents is protected.

WHAT IS surprising and disconcerting to mothers or couples in this situation is that genetic risk is usually given statistically, in percentages. The parents find themselves with difficult-to-interpret information while facing an unknown future. Conflicting values between marital partners or even within each of them increase the difficulty—and the anxiety.

Both genetic endowment and degree of disability are relative unknowns. For a recessive defective gene such as that for cystic fibrosis, when both parents are carriers the risk is 50 percent that the child will also be a carrier and 25 percent that the child will contract the disease. With this information, parents decide to proceed toward birth or to terminate the pregnancy. Later in the pregnancy the specific genetic makeup of a fetus can be discerned via amniocentesis and other tests.

In cases of Down Syndrome, for example, which is associated with trisomy (three copies of chromosome 21), eight out of every ten negative prenatal diagnoses lead to the decision to abort. Even though the genetic predisposition can be clearly identified in this way, the degree of mental retardation that will result is unknown. Mild cases mean near-average intelligence. Yet the choice to abort has become the virtual norm. The population of Down Syndrome people in our society is dropping, making this a form of eugenics by popular choice.

In only 3 to 5 percent of cases does a positive prenatal diagnosis reveal the presence of a genetic disorder so severe that the probable level of suffering on the part of the child warrants that a parent consider abortion. In making this judgment, I am invoking a principle of compassion—what bioethicists dub the principle of nonmaleficence, or reducing human suffering whenever possible. In situations where such a diagnosis is made and where prospective parents strongly desire to bring a child into the world, a number of things happen.

First, genetic counselors report that parents automatically refer to the child as a "baby," never as a "fetus." They clearly think of the life growing in the womb as a person. Second, when confronted with the bad news, they experience turmoil. The turmoil usually leads to a decision to terminate the pregnancy, but not always. It is not the job of the genetic counselor to encourage abortion; even advocates of choice on abortion defend the parents' right to decide to bring such a child to birth. Third, even when the decision to terminate is made, the grieving parents see their decision as an expression of their love, not a denial of love. It is an act of compassion.

The distinction between convenience and compassion is ethically significant here. As the practice of prenatal ge-

netic testing expands and the principle of autonomy—the responsibility for choice—is applied to the parents and not to the unborn child, the total number of abortions will increase, perhaps dramatically. Each pregnancy will be thought of as tentative until the fetus has passed dozens or hundreds of genetic tests. A culturally reinforced image of the desirable child—the perfect-child syndrome—may lead couples to try repeated pregnancies, terminating the undesirables and giving birth only to the "best" test passers. Those born in this fashion risk being commodified by their parents. In addition, those who might be born with a disability *and* with the potential for leading a productive and fulfilling life might never see the light of day.

A social byproduct of selective abortion might be increased discrimination against people living with disabilities. The assumption could grow that to live with a disability is to have a life not worth living. Persons with disabilities fear that the medical establishment and its supportive social policies will seek to prevent "future people like me" from ever being born. The inference is: "I am worthless to society." The imputation of dignity to handicapped persons may be quietly withdrawn as they are increasingly viewed as unnecessary and expensive appendages to an otherwise healthy society.

This would be a tragedy of the first order. Disabled persons deserve dignity and encouragement. Such people frequently gain victory in their difficult life struggles. Most disabled people report that while the disability, the pain, and the need for compensatory devices and assistance can produce considerable inconvenience, the inconveniences become minimal or even forgotten once individuals make the transition to living their everyday lives.

WHETHER we like it or not, the advancing frontier of genetics, with its impact on reproductive technology, thrusts us back into the abortion debate. *Roe v. Wade* (1973) did not answer the questions we will be asking in 2003. The Supreme Court decided that a woman has the right to abort during the first trimester. Genetic discrimination raises an additional question: by what criteria might a fetus be considered abortable? *Roe v. Wade* focuses on the woman's right to decide what to do with her body; now we focus on the fetuses and the criteria by which some will live and others will not. A skeptic might say that as long as the woman has the right to choose, it is a moot point to talk of criteria of choice. I believe that while a woman's right to choose is a legal matter, the criteria for choosing are an ethical matter.

Even though abortion on request is legal, not all grounds for requesting it are ethical. In the case of selective abortion, a decision based solely on the desires of the parents without regard for the child's well-being is unethical. As Martin Luther said, "Even if a child is unattractive when it is born, we nevertheless love it."

Most Christians are not ethically ready for the era of selective abortion. We are unprepared for the kind of decisions that large numbers of prospective parents will be confronting. We have thought about the issue of abortion on request and the question of when human dignity begins, but now we need middle axioms to guide the choices that will confront the next generation of parents.

First, we need to identify defective or undesirable genes prior to conception rather than after. Whether or not the conceptus has full personhood and full dignity comparable to living adults, ethicists agree that the fertilized zygote deserves a level of respect and honor that resists brute manipulation or irreverent discarding. Genetic selection in the sperm or ovum prior to fertilization, prior to the DNA blueprint of a potential person, seems more defensible.

Second, the choice for selective abortion should be the last resort. Prefertilization selection should be given priority when possible, as should prenatal gene therapy.

Third, the motive of compassion that seeks to minimize suffering on the part of children coming into the world should hold relative sway when choosing for or against selective abortion. Compassion, taken up as the principle of nonmaleficence in bioethics, constitutes the way that parents show love toward children-to-be. In rare cases (3 to 5 percent of prenatal diagnoses), the genetic disorder is so severe that no approximation to a fulfilling life is possible. The decision to abort can be understood as a form of caring for the baby as well as self-care for the parents. Yet it is still a judgment call. No clear rule tells us exactly when the imputed dignity of the unborn child may be trumped by a compassionate decision to abort.

Fourth, we should distinguish between acts of eugenics and acts of compassion. The goal of eugenics is to reduce the incidence of a certain genetic trait, usually an undesirable trait. Eugenics is social in scope and derives from some social philosophy. At this point, bioethicists tend to oppose eugenic policies because, if practiced on a large scale, they could reduce biodiversity. More important, eugenics connotes the political totalitarianism of the Third Reich. The compassion or nonmaleficence principle, when limited to the concrete situation of a family making a decision regarding a particular child, is much more acceptable. The line between eugenics and compassion is not a clear one, however. Some will argue that the attempt to eliminate a recessive gene for something like cystic fibrosis in future branches on a family tree is an act of compassion.

Fifth, we should distinguish between preventing suffering and enhancing genetic potential. Genetic selection to help reduce suffering is an act that, in at least a minimal sense, is directed toward the well-being of the child. In the future, when genetic selection and perhaps even genetic engineering make possible designer babies with higher-than-average intelligence, good looks or athletic prowess, then we will move closer to embracing the perfect-child syndrome. The risk of commodifying children and evaluating them according to standards of quality control increases when parents are "buying." The risk of commodification does not in itself constitute a reason to reject all genetic therapy, but it does call us to bolster a sound, biblically defensible principle: God loves people regardless of their genetic makeup, and we should do likewise. ■