Unnatural selection: Is evolving reproductive technology ushering in a new age of eugenics?
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Humanity has long dreamed of perfection, striving to be faster, stronger and brighter, pushing nature to the limit. Four centuries before people were conceived in a petri dish, Swiss alchemist Paracelsus claimed flawless little beings could be grown in pumpkins filled with urine and horse dung, but there is no record he produced a crop.

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With the birth of Louise Brown in 1978, the test tube finally succeeded where the pumpkin had failed, and the year she turned 11, scientists moved beyond making life in a lab: They found a way to peer into an embryo's genes and predict what that life might be like.

That ability is now morphing into a whole new approach to baby-making, one that gives people an unprecedented power to preview, and pick, the genetic traits of their prospective children.

Just as Paracelsus wrote that his recipe worked best if done in secret, modern science is quietly handing humanity something the quirky Renaissance scholar could only imagine: the capacity to harness our own evolution. We now have the potential to banish the genes that kill us, that make us susceptible to cancer, heart disease, depression, addictions and obesity, and to select those that may make us healthier, stronger, more intelligent.

The question is, should we?

It has been barely a year since the Supreme Court of Canada struck down the federal government's attempt to regulate assisted reproductive technology, handing the reins to the provinces, most of which have done nothing to fill the void.

During that year, fertility clinics across the country have begun to take advantage of the technology's latest tools. They are sending cells from embryos conceived here through in vitro fertilization (IVF) to private U.S. labs equipped to test them rapidly for an ever-growing list of genetic disorders that couples hope to avoid.

Recent breakthroughs have made it possible to scan every chromosome in a single embryonic cell, to test for genes involved in hundreds of “conditions,” some of which are clearly life-threatening while others are less dramatic and less certain – unlikely to strike until adulthood if they strike at all.
And science is far from finished. On the horizon are DNA microchips able to analyze more than a thousand traits at once, those linked not just to a child's health but to enhancements – genes that influence height, intelligence, hair, skin and eye colour and athletic ability.

Such tests were devised to help those suffering from infertility. But people well able to have babies the old-fashioned way now opt for IVF and embryo screening, paying a steep premium in return for the chance to have greater genetic control over their offspring.

Critics ranging from religious conservatives to advocates for the disabled worry that a new age of eugenics is rising, propelled not by racists, despots or elitists but by parental aspiration. Says Bernard Dickens, an expert in reproductive law and bioethics with the University of Toronto, this technology is “all part of the quest for the perfect child.”

That quest was once the domain of science fiction. But last year the U.S. National Aeronautics and Space Administration compiled a list of the most plausible sci-fi films. From thousands of candidates, NASA picked seven, led by the 1997 thriller Gattaca. Set in “the very near future,” it depicts a eugenic dystopia created by embryo screening, in which people born naturally suffer in the shadow of those who begin life in a lab.

In one scene, a geneticist reassures a couple that “this child is still you, simply the best of you. You could conceive naturally a thousand times and never get such a result.”

But the film's protagonist disagrees: “What began as a means to rid society of inheritable diseases has become a way to design your offspring – the line between health and enhancement blurred forever.”

It's a sobering prospect, yet in the real world, at least one prominent Oxford scholar supports such “unnatural selection” wholeheartedly, arguing that people who procreate are morally obliged to improve the species.

Many in the medical community also take a positive outlook.

“Parents are always choosing what they think is best for their children,” says Jeffrey Steinberg, whose Fertility Institutes has branches in Los Angeles, New York and, for those on a budget, Mexico. “The dilemma we've got,” he adds, “is that ... there are no rules.”

Dr. Steinberg, like many, sees the tests as a biological boon that could spare families and future generations from the burdens of disease, while Roger Pierson, a fertility specialist at the University of Saskatchewan, says governments can't ignore the economic implications. “We have an impending storm of health-care maintenance and cost issues.”

“We are not going to slow the technology, so the question is, how do we use it?” Dr. Pierson says. “Twenty years from now, you have to wonder if all babies will be conceived by IVF.”

What has Canadians flying down to Mexico?
It is 6:30 in the morning, and Dr. Steinberg is already on the job at the Fertility Institutes clinic in Guadalajara, which he visits from his base in Los Angeles every six weeks.

He offers IVF with embryos screened for a long list of conditions, and says his clients come from all over the world, including 10 to 15 couples a month from Canada – “a tenfold increase from five years ago, and the bulk of them are fertile.”

Because of “an old-line religious stance or new-line political correctness,” Dr. Steinberg says, most of his international clients can't have babies this way in their own countries.

Barring people from selecting the sex of a child was one of the few federal regulations the Supreme Court left intact, and the only restriction there is on embryo screening. Even still, couples face no repercussions for doing it out of country. Clients from certain cultures choose boys, but Dr. Steinberg finds Canadians tend to want girls.

“I don't see myself as a rebel,” he contends. “I'm just offering what the science allows.”

In the beginning, a way to bolster IVF

The science of embryo testing was born in a small London hospital in 1989. British scientist Alan Handyside, who had trained with test-tube-baby pioneers Patrick Steptoe and Robert Edwards, devised a method to extract a cell from a newly created embryo and amplify enough of its DNA to check for mutations. Doing so would allow doctors to implant in a woman's uterus only those embryos free of the mutation she wished to avoid.

Known as preimplantation genetic diagnosis, or PGD, it was billed by critics as a leap toward designer babies from the outset. But initially, few balked at its noble aims of eradicating hereditary diseases that can kill a child before kindergarten or result in catastrophic impairments, such as muscular dystrophy, Tay-Sachs and cystic fibrosis.

Yet this was before the human genome was mapped, and even Dr. Handyside says in an interview from London that “PGD was born prematurely.” Since then, genetic know-how has grown steadily, as have the uses of PGD, which is now employed to select a child's sex, to create “saviour siblings” genetically equipped with donor tissues to match those of another child in need and, ironically, to satisfy disabled couples who want to have children like themselves, most famously selecting traits to ensure deafness and dwarfism.

But its most common use by far is among doctors hoping to increase the pregnancy rates in women undergoing IVF, which now accounts for about 1 per cent of the 380,000 babies born in Canada every year. PGD can pinpoint abnormal embryos that carry a greater risk of miscarriage if implanted – a risk that increases exponentially with a woman's age.

Even countries that once took a hard line against PGD are changing their rules. Fertility clinics in Ireland plan to seek government approval this year to start screening embryos for serious diseases, and last year Germany gave PGD the go-head, overriding the strict embryo-protection act it had adopted when the procedure was invented.
And as demand grows, so do requests to detect a wider range of disorders: colon cancers, albinism, heart conditions, facial deformities. Natera (formerly the Gene Security Network), a California-based screening lab launched by multimillionaire Web entrepreneur Matt Rabinowitz, has even considered adding psoriasis to the list.

“Virtually any gene that’s identified we can include on a test,” Mr. Rabinowitz said after a talk last fall to Canadian fertility doctors in Toronto. His company’s ethics board regularly debates what genes to include and has stopped short of cosmetic traits: “We get calls. People want to test for eye colour – we won't do it.”

Dr. Steinberg’s work in Tinsel Town means that he is well acquainted with such desires. “We get requests for all kinds of things. We had a pop star inquiring if her vocal abilities could be passed on to her children,” and elite athletes asking, “Do you think you could make it a tall boy?”

So when he went to a conference in 2009 and met scientists who had identified genes that influence eye, hair and skin colour in the people of Iceland, he assumed that his clients would be interested and struck a deal to offer tests for those genes. Then he posted the news on his clinic’s website, and “the whole world went ballistic.”

Media converged from as far away as Europe, so many reporters and cameras that he couldn’t get through the door. Television talk shows said folks would be able to customize their kids as they do their iPods.

Then the Vatican called. A soft-spoken papal executive said “he realized these things might be possible, that people might want these things,” Dr. Steinberg recalls. “But, please,’ he asked, ‘can you just slow down?’”

Dr. Steinberg agreed to do so, but not before an article appeared in the Los Angeles Times by a Washington man who had tried to use PGD to produce a sibling to save his mortally ill son. Allen Goldberg called it a corruption to use the technology to test for cosmetic characteristics. “What I now fear,” he wrote, “is that ... trait selection to satisfy the whims of parents will turn people against a procedure that can save lives.”

The screening pioneer who had a change of heart

Last fall, not far from the Guadalajara clinic where Dr. Steinberg helps couples have children without disabilities, Canadian researcher Jeffrey Nisker was attending the 2011 Paralympics, cheering on a friend who was among the athletes.

Twenty years ago, Dr. Nisker also was a PGD pioneer helping to push the boundaries of the technology, but, unlike Dr. Steinberg, rather than slow down when ethics became a concern, he stopped altogether.

Working at the University of Western Ontario, he had come up with a method for extracting cells that allowed more embryos to survive PGD. With the help of a “huge grant,” he says, his clinic quickly became second only to the hospital where the procedure was born.
Then, he considered PGD a triumph – a way to have children without lethal diseases, while sparing pregnant women from amniocentesis, the genetic test that relies on the withdrawal of fetal cells and can trigger a miscarriage, as well as the prospect of an abortion.

“I was enamoured by the science,” Dr. Nisker says. “But, you know, I had never really thought about where it was going.”

That changed when news of his clinic's first PGD pregnancies hit the media. He was deluged with calls, but few came from couples eager to avoid diseases. Most wanted “to choose the sex of their children, to select for this or that,” he says.

Even more surprising: “Fifty-eight per cent of the calls were from fertile couples. I never thought for one minute this would be used by fertile couples.”

Before long, he says, “it was getting crazy … My friends would say: ‘Don't you see where this is going?’ And they were absolutely right. I shut the lab and gave the money back.”

A year later, in 1994, his concerns and desire for public discussion led him to write Orchids, a provocative play in which a doctor lecturing medical students says: “In a perfect world, exploration of the ethical and social implications of genetic science should precede research … Without careful constraints, the rapid pace ... may be harmful.”

Today, he still hopes for a full public debate, worried that screening out genetic defects will create a cold, intolerant world like the one portrayed in Gattaca: “This is scary to me because I'm one who doesn't believe in social engineering. If we strive for perfection, we are going to blame people with disabilities. We're not going to accommodate them, or support them with tax dollars.”

Santiago Munné, a PGD pioneer in the United States, says advocates for the disabled understandably oppose the procedure since they are “fighting for resources to support these kids.” But “the ethics of doing PGD are much better than terminating a pregnancy. We're not doing that – we're just not transferring [into a woman's uterus] any embryos that have genetic diseases.”

But to those who believe that life begins at conception – even if it takes place in a petri dish – there is no difference. In a 2006 submission to Health Canada, the Catholic Organization for Life and Family called for a ban on PGD, saying it “inherently disrespects the dignity and worth of human life, since it is performed in order to select the most genetically perfect embryos while discarding those that are deemed undesirable.

“Parents, doctors and society become ... the arbitrators of life or death.”

PGD parents wrestle with ethical implications

The idea that they may be playing God has not escaped those who have tried PGD, or thought about trying it. The topic makes many parents uncomfortable – several couples turned down requests for interviews, including Canadians among Dr. Steinberg's clients in Mexico.
But many are more candid with the anonymity provided by online fertility forums. For instance, an Australian mother of two sons recently wrote that she had intended to use screening to have a daughter but had a last-minute change of heart – “PGD felt too much like I was playing God,” she said, adding, “I know I'm pregnant with a girl. Don't know how I know but I just do.”

Another woman, who had used PGD to avoid passing down a syndrome that results in severe facial deformities, countered that she “doesn't really get the playing-God argument. ... I think IVF is unnatural – but so is driving a car.”

A 47-year-old woman who had relied on donor eggs, and underwent IVF and PGD intending to conceive a boy as the fifth-generation namesake in her husband's family, said: “I don't feel that we are playing God at all. ... No one but God can decide what sex the embryos are going to be.” Indeed, all her healthy embryos turned out to be girls.

About the same time that Dr. Steinberg was riling the Pope, Health Canada asked Dr. Nisker to find out how Canadians were using PGD, which led to a 2009 study that he says is already out of date. But he and sociologist Susan Cox of the University of British Columbia revived Orchids for a national tour, quizzing audiences to get an idea of how Canadians feel about the technology.

Of the 950 respondents, he says, “most were worried that government or doctors would draw the line around what could be tested. People were happier with everyone drawing their own lines, even if they were also worried about what would happen to the disabled.”

In fact, despite his own fears and 15 years of pushing for regulations, Dr. Nisker agrees that universal limits are tough to set, given that PGD is also embedded in the freedom of reproductive choice.

As Prof. Dickens, the U of T expert in reproductive law and bioethics, explains: “It is not clear that the government can, or should, intervene.”

In some cases, PGD can be seen as a public-health triumph, he says, citing its profound effect on Ashkenazi Jewish communities that have a high risk of passing on Tay-Sachs, a neurodegenerative disease that usually kills a child by the age of 4.

If both parents carry the gene, chances are one in four their child will be afflicted. Two carriers used to be advised not to marry, or relied on amniocentesis and abortions. (A prenatal screening program of this type helped to reduce Tay-Sachs in Montreal's Jewish and Mediterranean communities by more than 95 per cent.)

But with PGD, couples can take evolution into their own hands, implanting embryos not only free of the disease, but those that carry no copies of the defective gene at all – eliminating the risk of Tay-Sachs to future generations.

And while Prof. Dickens agrees that using PGD for cosmetic traits rather than life-and-death conditions is “questionable,” he doesn't rule it out. “If this is being funded by the individual, it is hard to limit.”
Unlike the U.S. and Canada, Britain strictly regulates genetic selection, permitting it only for inherited disorders deemed serious enough to warrant discarding embryos that carry them. Every addition to the test list requires formal permission and, to date, 130 have been approved.

Dr. Handyside is not a fan of his government's approach. “It's just added a whole layer of bureaucracy. It makes parents feel like pariahs.”

Now at the London Bridge Fertility, Gynecology and Genetics Centre (whose website calls him “the father of PGD”), he recently wrote a commentary in the journal Nature, acknowledging that the new screening technologies “come with ethical and social challenges” and “are bound to increase demands from prospective parents who want to know, or control, how their child will turn out.”

But Dr. Handyside feels that most couples are not interested in cosmetics – “they just want a healthy child” – and should be able to decide for themselves what they wish to avoid. The market polices itself, he says, pointing out that condemnation from the public and his own peers prompted Dr. Steinberg to withdraw his offer to test for eye, hair and skin colour.

Yet most screening decisions are made in private, between patients, their doctors and the ethics-review boards that clinics convene. But in Britain, all PGD testing is a matter of public record, and often, controversy.

In 2007, for instance, doctors were condemned for enabling a couple to avoid having their baby inherit a severe squint that prevented the father and grandfather from looking anywhere but down or to the side. Dr. Handyside says the father had undergone several operations to ease the condition, which “had blighted his life, and he didn't want to pass it on to his children.” Even conditions that seem mild can have a serious effect, he adds.

Which is why trying to restrict embryo tests to health-related conditions provides no easy answers: Should it include those that are mild or manageable, those that only increase disease risk, or only develop later in life?

Such questions are ever more pressing, says Marcy Darnovsky of the California-based Center for Genetics and Society: “Many people live happy, fulfilling lives with the conditions we're trying to weed out.”

Seang Lin Tan, a renowned fertility specialist at McGill University who worked with Britain's IVF pioneers, agrees that the technology comes with tricky ethical issues. To him, the most vexing is whether embryos should be discarded for carrying disease genes that may not have an effect until well into adulthood.

Dr. Tan, also medical director of the Montreal Reproductive Centre, dismisses as “a lot of hype” the fear that couples will use PGD to make blond, blue-eyed babies. But he sympathizes with those who fear that the future may bring, say, breast cancer: “If you have this disease in your family ... and you're doing PGD anyway, I think it's reasonable.”
Last January, Dr. Tan says, his Montreal clinic became the first in Canada to begin shipping cells to Reprogenetics, a New Jersey laboratory established by Dr. Munné, the PGD pioneer, that runs non-stop – even on Christmas Day.

Quebec is the only province to fund IVF (providing only a single embryo is implanted to avoid the costs and risks linked to multiple births), now subsidizes a basic form of PGD.

Technology now available in Canada scans only a small fraction of chromosomes, Dr. Tan says, and a recent study in the New England Journal of Medicine found that the older tools can actually hurt pregnancy rates. Which is why his patients are willing to pay a premium of roughly $5,000.

The Reprogenetics chip can scrutinize abnormalities in all 23 pairs of chromosomes simultaneously, and demand is so steady that Dr. Munné, who serves at least 10 Canadian clinics, says he may open a branch north of the border.

Dr. Tan's wife, Grace, who is director of McGill's medical MBA program and often helps out at the clinic, says patients who opt for PGD often are older and "very stressed – they have had repeated miscarriages and repeated abortions. To know they received a normal embryo gives them hope."

One woman was determined to avoid the genetic mutation that causes webbed feet in her husband's family. But all 10 of the embryos the couple conceived by IVF carried the mutation.

Rather than have any of them implanted, she opted to use donor sperm and bear a child with normal feet but no biological tie to her husband.

“There's no doubt that this area is a slippery slope,” Dr. Tan says. “But at the end of the day, this technology evolves in pace with society's values.”

The New York University School of Medicine surveyed 999 people in 2009 and found that most supported prenatal screening to eliminate serious diseases, along with mental retardation (75 per cent) and blindness (56 per cent). At least 10 per cent also favoured improving height and 13 per cent considered superior intelligence acceptable.

But Julian Savulescu, the controversial Oxford University bioethicist, believes that society must do more than be tolerant. He claims parents have a moral obligation to select embryos that are “most likely to have the best life, based on the available genetic information.”

That information, he argues, should not be limited to avoiding disease genes, but should include those that might improve intelligence or physical characteristics – even if it maintains or adds to social inequalities. He calls it “procreative beneficence.”

Prof. Savulescu, whom Dr. Nisker has often debated, also believes that society should embrace the genetic manipulation of embryos to endow future offspring with superior traits that inheritance has not provided. Until recently, such engineering was only theoretical. But in 2007, researchers at Cornell University quietly created the world’s first genetically modified human embryo by adding a fluorescent gene that allowed scientists to watch it develop. The breakthrough did not become
public until the following year, when it was roundly condemned as a worrisome step toward designer babies.

Despite the evolutionary aspirations of people like Prof. Savulescu, Ms. Darnovsky of the Center for Genetics and Society suspects that PGD is too expensive and invasive to be adopted widely. But even with limited use, she says, “the danger is we would be reinforcing the inequalities we already have to a shameful degree and introduce new inequalities where only some people have these traits.”

She also worries that parents who go to great lengths to stack the genetic deck of their children will place undue expectations on them. “In a way, it's a closing off of the child's future,” she says, since the parents have tried to predetermine what their strengths should be.

What's more, parents who turn to PGD as a means to avoid a specific condition may also decide to test for other traits while they are at it. “I think that what happens,” Ms. Darnovsky says, “is that we start to look at our children as we look at remodelling,” as when painting the front porch somehow leads to a full home renovation.

Dr. Steinberg agrees. “People might say one thing publicly about what they'd want in their children, but when you sit down and talk about we're going to do, they start asking about other things: intelligence and height.”

Regardless of what people want, Dr. Handyside insists that the concept of the “designer baby … has no merit.” PGD is limited by the genes the parents already have, he says. As well, the number of embryos parents have to choose from is limited by the fact that often only a few can be created by IVF at a time – making it extremely unlikely that any one could cherry-pick a desired combination of traits to produce, say, a blond, muscular Mozart.

“There are over eight million possible genetic combinations,” he says. Even still, the selected embryo could be miscarried or develop a mutation in the womb. At best, he says, “the genetic snapshot will provide a fuzzy photo of each of your prospective children.”

Jonathan Kimmelman, a genetics researcher and bioethicist at McGill, notes that, while science has made it feasible to select against certain genes, selecting for them to predict traits is much trickier. “Genes are not determinants,” he says, adding that a great many of them have a very small impact on the same characteristics and “interact with environmental cues about which we know very little.”

Yet, to some who offer embryo screening, the limited power of genes bolsters the argument that it is harmless to select them.

“Parents make crucial decisions for their children all the time – where children are educated, how they are raised, how they feed them,” says Mr. Rabinowitz of Natera. “In a way, this is not so different.”

But Dr. Kimmelman says there is a crucial distinction: “When you put your child in a private school, the child interacts with the [environment]; he or she has a choice about how they interact with it …. But when you make a medical decision, it results in a biological cascade of events in which they have no choice.”
And despite all its advances, science still knows too little about how genes function. Some do more than one job – genes involved in sickle cell anemia, for instance, also play a role in protecting against malaria. Is it possible that the genes judged undesirable could come back to haunt us?

“The history of medicine,” Dr. Kimmelman notes, “is filled with unintended consequences.”

Preconception screening, or ‘offspring projections'

Dr. Handyside predicts that one day soon parents will know long before sperm meets egg what ills may befall their children. Studies estimate that unknowingly we all carry genes linked to three or more diseases – he recently discovered that his include cystic fibrosis.

“The 21st-century couple is going to say, ‘Right, we want to start a family,’ and then they get a $1,000 gene test and see what ... they carry that might get passed on.”

In the U.S., the future has already arrived as companies have begun to offer preconception screening. Existence Genetics in California calls it “offspring projections,” and analyzes the entire genomes of two people “to determine which diseases and traits their offspring are likely to inherit.”

Company founder Brandon Colby says that, in a way, his genes determined his future. Growing up in Long Island, N.Y., he was never allowed to run or play field sports with the other boys.

“Why?” he asked his parents.

“Because of your genes,” they replied.

Born with epidermolysis bullosa simplex, an incurable genetic condition, he breaks out in painful blisters on his hands and feet when exposed to heat and friction. As a child, he had to be held down while they were lanced.

Now 33, Dr. Colby is a geneticist with a business degree from Stanford and a company with a microchip that can test a remarkable 1,500 genetic traits at once, including heart disease, seasonal affective disorder, obesity, athletic ability, hair and eye colour, height, susceptibility to alcohol and nicotine addictions, lactose intolerance and one of several genes linked to intelligence. This particular gene has been shown to result in a seven-point IQ gain if a baby is also breast-fed, he says: “We're interested in using the genetic information that will allow parents to take action.”

Still, a technical hurdle remains – figuring out how to amplify enough DNA from a single embryonic cell to run such an extensive test. But Dr. Colby is confident that the answer is coming soon, just as he is certain that “PGD will be part of my reproductive future.”

He is determined not to hand down his skin condition, even if he has thrived despite it – becoming a doctor, building a business and writing a book (called Outsmart Your Genes). He has even found a way to exercise – cruising the hillsides of Santa Barbara on a bicycle with custom-made, non-friction handlebars and special shoes.
“I have wrestled with this idea, that if this technology had been available to my parents, I might not be here. But then someone else would be and, hopefully, that person would have had the same value of a life.”

Of course, even erasing his own existence seems insignificant compared with his plans for shaping the future. Eventually, “we're going to see most [major] diseases fade from existence,” he says.

“Our next major leap of evolution as a species will be one that we control.”

Editor's note: The Center for Genetics and Society is based in California. Incorrect information appeared in an earlier version of this article.