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From sex selection to surrogates, American IVF clinics provide services outlawed elsewhere



Embryologist Heather Marks opens one of several nitrogen tanks that collectively hold tens of thousands of frozen embryos and eggs at New Hope Fertility Center in New York City on Dec. 20, 2017. (Carolyn Van Houten/The Washington Post)

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Danielle Lloyd, a former Miss Great Britain and celebrity mother of four boys, wants to guarantee that her next baby will be a girl. So, she revealed in a TV interview last year, she's planning to get pregnant through in vitro fertilization.

The news sparked an uproar in Britain, where screening embryos for gender is prohibited at IVF clinics. Unruffled, Lloyd, 35, began checking out clinics in the few

places on the planet where the service is readily available: Cyprus, the United Arab Emirates — and the United States.

"I can see why people are against it, and I don't want to upset anyone," Lloyd said. "But I can't see myself living not having a daughter when I know it's possible."

While many countries have moved in recent years to impose boundaries on assisted reproduction, the U.S. fertility industry remains largely unregulated and routinely offers services outlawed elsewhere. As a result, the United States has emerged as a popular destination for IVF patients from around the world seeking controversial services — not just sex selection, but commercial surrogacy, anonymous sperm donation and screening for physical characteristics such as eye color.

This freewheeling approach has been good for business; the U.S. fertility industry is estimated to be worth as much as \$5.8 billion this year. But as technological advances outpace any social consensus on such forms of reproductive intervention, discomfort with the hands-off status quo is rising.

Last month, news that a U.S.-educated Chinese researcher had created the world's first gene-edited infants reignited a debate over the morality of "designer babies." Some scientific leaders blasted the effort, which purported to make the babies resistant to HIV infection, and urged the U.S. government to step in.



Francis Collins, director of the National Institutes of Health, said he is concerned about the use of in vitro fertilization to screen for particular characteristics. (Kristoffer Tripplaar/For The Washington Post)

In an interview, National Institutes of Health Director Francis Collins condemned the geneediting experiment as an "epic scientific misadventure," and said he is seeking to establish a forum for oversight and public debate about the technology and related areas of science.

Collins said he also is concerned about the rise in the screening of embryos for characteristics such as intelligence, physical appearance and gender. Although editing a baby's DNA is fundamentally different from picking and choosing among embryos created by nature,

the procedures raise similar ethical questions about manipulating human reproduction.

"IVF clinics have had pretty free rein, and some would look at their pathway as being a bit free and easy in terms of new developments," Collins said, adding that U.S. clinics have "a bit of a reputation of being cowboys." "They help a lot of people . . . and that's largely a good thing," he said. "But one might wonder if there is a need for more oversight than we currently have."

A political compromise

The story of how assisted reproduction escaped regulation in the United States begins in the 1990s, when national politics were riven by disputes over procreation, contraception and abortion. Abortion doctor David Gunn was killed by an antiabortion activist in 1993, and the nation's abortion clinics were under siege.

Amid this tumult, a panel of scientists, legal experts and ethicists convened by NIH released a report in 1994 on research involving human embryos. The report called for federal funding to explore this "sensitive and vital area of biomedical science." It also emphasized the need for regulation and voiced "serious ethical concerns" about sex selection in IVF.

Gender selection is possible in IVF through a process known as preimplantation genetic diagnosis, or PGD. Clinicians take a single cell or a few cells from an embryo and use DNA probes to examine its genetic makeup.

While PGD is typically used to screen embryos for inherited diseases, it also can be used to identify embryos with characteristics parents find desirable. For example, deaf people and people with dwarfism may want children who share those traits. Other people may want a child who is a compatible tissue donor for a sick sibling.

PGD does not change the embryo but helps would-be parents choose which embryos to transfer to the womb — and which to discard.

The idea that embryos might be created and then destroyed as part of this new science did not sit well with religious conservatives, who believe that life begins at conception. So in 1995, then-Reps. Jay Woodson Dickey Jr. (R-Ark.) and Roger Wicker (R-Miss.) added a provision to an appropriations bill that did the opposite of what the NIH paper proposed. Instead of supporting research and government regulation, it prohibited the expenditure of federal funds for any research that involves the creation or destruction of human embryos.

The amendment was intended to help skittish lawmakers navigate a touchy issue, allowing them to vote against public funding for embryo research while permitting such research to continue in the private sphere.

The ban, which remains in effect, "laid the backdrop for a more hands-off regulatory approach," said Michelle Bayefsky, a former bioethics fellow at NIH who has written a book about PGD.

The debate evolved very differently on the other side of the Atlantic. Like the United States, Britain put together an expert panel to study assisted reproduction. The panel suggested the establishment of a public body to oversee human embryo research, regulate fertility clinics and take the lead on debates about new technologies. Parliament concurred and in 1990 established the Human Fertilization and Embryology Authority, the first statutory body of its kind and a model emulated by other countries.

Today, the HFEA is overseen by Peter Thompson, a career government official who previously worked in the Ministry of Justice and the Cabinet Office. Thompson directs a staff of 70 that includes clinic inspectors stationed throughout the country, and oversees a board of scientists, ethicists and theologians who debate the larger issues.



Danielle Lloyd, Miss England 2004 and Miss Great Britain 2006, plans to conceive by in vitro fertilization to have a girl. She has four boys. (Chris Ison/AP)

"Our rules are stringent enough to provide public trust, and flexible enough to allow scientists to innovate," said Thompson, who described his agency as "a bargain between science and society."

Britain's stance on "three-parent" babies offers an example of the HFEA's approach. The treatment is offered only to women with serious diseases that could be transferred to a baby through mitochondria in their eggs. DNA from the mother is injected into an egg from a healthy donor. The egg is then fertilized with the father's sperm, and the resulting embryo is genetically related to both parents.

In the United States, the legality of this procedure is unclear. The Food and Drug Administration issued a warning letter in August 2017 to a New York doctor who had used the technology to help a couple afflicted

by a serious inherited illness; the doctor, <u>John Zhang</u>, also had hoped to use it to help older women whose eggs have degraded. The FDA warning essentially brought such work to a standstill in the United States.

Meanwhile, Britain in 2017 became the first country to formally license the procedure — though only for women with heritable diseases. While no babies have

been born yet, Thompson said several women are undergoing the procedure at Newcastle University.

HFEA takes a similar approach to gender selection, permitting it only when a parent carries a heritable disease that affects just one sex.

"These treatments are not being used for nonserious matters," Thompson said. "These are really unpleasant illnesses. The majority of the British public feel these interventions are justifiable where harm is that great."

Numerous other countries also are tightening their regulation of the fertility industry. Last year, India banned commercial surrogacy. Next year, Ireland is set to join the Netherlands, Norway, Sweden, Switzerland, Finland, New Zealand and others in prohibiting anonymous sperm donation. And a large number of countries — including China, Canada and Australia — ban gender selection except in rare cases of medical need.

'Asking for all kinds of things'

A decade ago, American society was similarly concerned with the moral aspect of these procedures. Jeffrey Steinberg, a fertility specialist in Encino, Calif., remembers the wave of outrage that arose when his clinic became one of the first to offer parents the ability to choose not only the gender of their child but also eye, skin and hair color.

Critics accused him of practicing eugenics. Hate mail poured in from the religious right, albino support groups and others. Journalist Dan Rather camped out in his clinic parking lot.

After a few weeks of chaos, Steinberg dropped the offer of cosmetic screening for pigmentation, posting a note on the clinic's website. "Though well-intended," it said, "we remain sensitive to public perception and feel that any benefit the diagnostic studies may offer are far outweighed by the apparent negative societal impacts involved."

Steinberg continued offering tests for gender and eye color, however, at his California clinic and in Mexico. Over the years, as his clientele grew, gender screening was quietly adopted by IVF clinics across the nation as a standard service.

A survey published in March in the <u>Journal of Assisted Reproduction and</u> <u>Genetics</u> found that nearly 73 percent of U.S. fertility clinics offer gender selection. Of those, nearly 84 percent offer it to couples who do not have fertility problems but are considering IVF solely to control the pregnancy's outcome.



Chrissy Teigen and baby Luna are seen in New York City. Teigen indicated in a 2016 interview that Luna was conceived by IVF. (Robert Kamau/GC Images)

Model and cookbook author Chrissy Teigen is among the satisfied customers. Teigen, who sought IVF for infertility issues, tweeted in 2016 that she was pregnant with a daughter, adding in a magazine interview: "I picked the girl from her little embryo." Meanwhile, international agencies with names such as Gender Selection Australia say they are sending thousands of patients a year to IVF clinics in the United States to take advantage of the service.

And Steinberg says would-be parents are starting to demand even more screening options. He estimates that he has helped 70 couples screen for eye color (the success rate is about 60 percent — a little better than a coin flip) and is working with 20 more. Blue is the most-requested color, followed by green.

"People call up asking for all kinds of things: Vocal ability, athletic ability. Height is a big one. I have a lot of patients who want tall children,"

he said.

So far, Steinberg and other fertility specialists have not been able to identify the genes that drive those traits. But he believes they will be found. And when that happens, he will offer to screen for them.

"If you do what I do, you can't have a strong ethical opinion," he said, unless parents ask for "something that is going to be harmful."

The technology is moving fast. One biotechnology company, Myome, says it will soon offer couples undergoing IVF the ability to identify embryos most likely to grow into healthy adults by calculating their risk of a wide spectrum of diseases and disorders. Another company, Genomic Prediction, is rolling out an intelligence screening service that it says will help parents identify and reject embryos with a higher risk of growing into children with lower IQs.

This spirit of experimentation has made the United States a popular destination for wealthy fertility patients from around the world — particularly China, where gender selection is largely prohibited.

Last month, Steinberg spoke at a conference in Beijing at the invitation of a Chinabased fertility travel agency. He was treated like a celebrity: The agency put him up at the Four Seasons hotel and, after his talk, prospective parents mobbed him, forming lines that snaked around the hall. He stayed until well past midnight talking with hopeful couples. Within weeks, five of them had flown to his California clinic. As for Lloyd, the former Miss Great Britain, she has made tentative plans to start IVF treatment this summer in the UAE.

Although Cyprus was appealing on price — about a third what it costs elsewhere, she said — a doctor friend warned her about a troubling record of mix-ups. So she narrowed her search to clinics in Los Angeles and Dubai, one of the UAE's seven emirates.

Clinics in both countries quoted more or less the same price: about \$25,000 per cycle. But the flight from Britain to Dubai takes just eight hours, while Los Angeles is nearly 11 hours away. Plus, Lloyd's family is familiar with Dubai, having visited on vacation.

While Lloyd said she is respectful of the British law banning gender selection and does not think it should be changed, she said she longs for the kind of motherdaughter relationship she has with her own mother. With four boys ages 8, 7, 5 and 1, Lloyd said she feels fortunate that places exist where she can fulfill her desire for "family balancing."

But Lloyd said she has no interest in any other form of screening, whether for eye color or height.

"There's no need to do something like that," she said. "All I want is a healthy baby girl. I don't care what she looks like."

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