



## Babies with made-to-order defects?

Prenatal testing creates controversial options for parents with disabilities

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The power to create "perfect" designer babies looms over the world of prenatal testing.

But what if doctors started doing the opposite?

Creating made-to-order babies with genetic defects would seem to be an ethical minefield, but to some parents with disabilities — say, deafness or dwarfism — it just means making babies like them.

And a recent survey of U.S. clinics that offer embryo screening suggests it's already happening.

Three percent, or four clinics surveyed, said they have provided the costly, complicated procedure to help families create children with a disability.

Some doctors have denounced the practice; others question whether it's true. Blogs are abuzz with the news, with armchair critics saying the phenomenon, if real, is taking the concept of designer babies way too far.

"Old fear: designer babies. New fear: deformer babies," the online magazine Slate wrote, calling it "the deliberate crippling of children."

But the survey also has led to a debate about the definition of "normal" and inspires a glimpse into deaf and dwarf cultures where many people do not consider themselves disabled.

Cara Reynolds of Collingswood, N.J., who considered embryo screening but now plans to adopt a dwarf baby, is outraged by the criticism.

"You cannot tell me that I cannot have a child who's going to look like me," Reynolds said. "It's just unbelievably presumptuous and they're playing God."

### Crossing bounds?

Embryo screening, formally called preimplantation genetic diagnosis, is done with in vitro fertilization, when eggs and sperm are mixed in a lab dish and then implanted into the womb. In PGD, before implantation, a cell from a days-old embryo is removed to allow doctors to examine it for genetic defects.

The entire procedure can cost more than \$15,000 per try.

The survey asked 415 clinics to participate, 190 responded and 137 said they have provided embryo screening. The most common reason was to detect and discard embryos with abnormalities involving a missing or extra chromosome, which can result in miscarriage or severe and usually fatal birth defects.

The survey is being published in an upcoming print edition of the medical journal *Fertility and Sterility*. It appeared in the online edition in September. Clinics were asked many questions about PGD, including whether they'd provided it to families "seeking to select an embryo for the presence of a disability."

"We asked the question because this is an issue that has been raised primarily by bioethicists as something that could happen," said Susannah Baruch of Johns Hopkins University's Genetics and Public Policy Center.

"It's sparking a lot of conversations," she said. "These are difficult issues for everybody."

While it's technologically possible, whether any deaf or dwarf babies have been born as a result of PGD is uncertain. The survey didn't ask. Participating clinics were promised anonymity, and seven major PGD programs contacted by The Associated Press all said they had never been asked to use the procedure for that purpose.

PGD pioneer Dr. Mark Hughes, who runs a Detroit laboratory that does the screening for many fertility

programs nationwide, said he hadn't heard of the technology being used to select an abnormal embryo until the survey.

"It's total nonsense," Hughes said. "It couldn't possibly be 3 percent of the clinics" doing PGD for this purpose "because we work with them all."

He said he wouldn't do the procedure if asked.

"To create a child with a disability because a parent wanted such a thing ... where would you draw the line?" Hughes wondered.

"It's just unethical and inappropriate, because the purpose of medicine is to diagnose and treat and hopefully cure disease," he said.

For the same reasons, Yury Verlinsky, another PGD pioneer and director of Chicago's Reproductive Genetics Institute, said he also would shun those requests.

Dr. Jeffrey Steinberg, whose Fertility Institutes clinics in Los Angeles, Las Vegas and Guadalajara, Mexico, screen embryos for sex selection, said he'd likely consult ethicists if he were ever asked to help couples select a deaf or dwarf baby.

"Clearly it crosses some bounds," he said.

He'd get a provocative response from University of Minnesota bioethicist Jeffrey Kahn.

"It's an ethically challenging question and certainly it will trouble people, but I think there are good, thoughtful reasons why people who are deaf or ... dwarves could say, 'I want a child like me,'" Kahn said.

The traits are, for some, an important part of their cultural identity.

"If people in a shared culture all have the common clinical defect, then it's maybe not a defect in the traditional sense," Kahn said.

More challenging would be if normal-sized parents said they wanted a dwarf child, and yet, he added, "Why is that different from dwarf parents saying, 'We want only an average-size child?'"

#### **'Fully functional human beings'**

Dr. Jamie Grifo of New York University, a past president of the Society for Assisted Reproductive Technology, has done embryo screening for more than a decade and said if it is being used to choose defective embryos, it certainly isn't common. Cost is one thing. But IVF alone requires weeks of injections with ovary-stimulating drugs and surgery, and couples generally have a less than 50-50 chance of a baby with each IVF-PGD cycle, Grifo said.

Grifo said he wouldn't oppose embryo screening to select a baby with a genetic defect if the parents have been informed of the pros and cons, risks and benefits.

"In our society, people are so quick to have knee-jerk reactions to something that's none of their business," he said.

Despite some teasing and childhood surgery to fix dwarfism-related bone deformities, Reynolds said she considers herself "very lucky. I have a wonderful husband and a beautiful life."

Their newborn daughter died last year from a devastating dwarfism-related disease called homozygous achondroplasia. Dwarf couples have a 25 percent chance of having babies afflicted with the lethal condition, the same odds of having "normal" children, but a 50 percent chance of having dwarf children.

When the couple consulted a specialist earlier this year about embryo screening to avoid a similar tragedy, they discussed implanting dwarf or non-dwarf embryos.

"A healthy dwarf embryo is a healthy embryo. It's a kid who's going to go to school, go to college and make friends," Reynolds said she told the specialist, and he wasn't opposed to the idea. But she decided against the procedure because her insurance didn't cover it and her age — 39 — limited chances for success.

Karen Krogstad, a 25-year-old partly deaf student in Bozeman, Mont., said she understands why parents "would go to great lengths to make sure their child will be deaf."

She and her deaf friends "see ourselves as fully functional human beings who can't hear. People who wear glasses, are they disabled? No, but if you have hearing aids, to assist with hearing, you are labeled as disabled."

Krogstad said she wants children someday and would be happy with a deaf or non-deaf child. But she said she wouldn't use embryo screening to have a deaf child "because I think it is wrong to choose the perfect baby."

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