Audiologists are devoted to helping people hear better, so it will likely come as a shock to learn that some parents prefer that their babies be born deaf. So-called designer deafness is the idea behind conceiving a deaf child via preimplantation genetic diagnosis or by selecting a sperm or egg donor with a strong family history of deafness.

A deaf couple from Maryland, Candace McCullough and Sharon Duchesneau, made headlines in 2002 when they spoke with The Washington Post about their decision to seek out a deaf sperm donor. (The Washington Post March 31, 2002.) (See FastLinks.) The donor had generations of deafness in his family, and Ms. McCullough and Ms. Duchesneau wanted to ensure that their children, Jehanne and Gauvin, would also be deaf. It’s not illegal in the United States to use assisted reproductive technology to try to conceive a deaf child, though the couple was turned down by several sperm banks before turning to a family friend.

“Some people look at it like, ‘You shouldn’t have a child who has a disability.’ But, you know, black people have harder lives. Why shouldn’t parents be able to go ahead and pick a black donor if that’s what they want,” Ms. McCullough asked the Post in 2002. “They should have that option. They can feel related to that culture, bonded with that culture.”

Several years later, a British couple, Thomas Lichy and Paula Garfield, protested against laws that would prohibit selecting a disabled embryo when a normal one was available. The proposed amendment was specifically aimed at situations in which deaf parents tried to use assisted reproduction to produce or select deaf embryos. (The Telegraph April 13, 2008.) (See FastLinks.)

Sixty percent of hearing children with deaf parents said technology should not be used to select for deafness

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THE CASE FOR SELECTING DEAFNESS

To a hearing person — and to some deaf people — the idea of trying to guarantee your child’s deafness may seem shocking. Deafness, proponents say, is linked to a unique sense of community, and many deaf people consider it a culture, something that deaf parents wish to share with their children. Others believe that deafness is a disability, and deliberately choosing to deny a child the ability to hear is tantamount to abuse.

Challenging this perception is Melissa Seymour Fahmy, PhD, a professor of philosophy at the University of Georgia in Athens. She pointed out that parents who use preimplantation genetic diagnosis to select a deaf embryo rather than a hearing one do not take hearing away from a hearing child but allow a deaf child to be born. (Bioethics 2011;25[3]:128.) Dr. Fahmy said no technology exists to make such an embryo develop into a hearing child; it will be born deaf or not at all. The question then becomes, is it morally wrong to choose a deaf embryo over a hearing one?

Hearing children of deaf parents, a group with a unique dual perspective, appear to be ambivalent about using reproductive technologies to deliberately select deaf embryos. Martin Delatycki, a pediatric geneticist and the director of the Bruce Lefroy Centre for Genetic Health Research at Royal Children’s Hospital in Victoria, Australia, reported that while 72.3 percent of these children have no preference for or against having a deaf child themselves, 60 percent said reproductive technologies should not be used to select for or against deafness. (J Med Ethics 2009;35[12]:722.)
Dr. Fahmy, who completed the article a couple of years before its publication, was unavailable to discuss her theories because of teaching commitments. Ms. McCullough and Ms. Duchesneau declined to be interviewed, and Mr. Lichy and Ms. Garfield did not respond to inquiries from The Hearing Journal. Mr. Delatycki, however, offered his thoughts on this complex and challenging issue.

**HJ**: How common is interest among deaf parents in using in vitro fertilization with preimplantation genetic diagnosis to select for deafness in their children?

Mr. Delatycki: It is rare that this is requested in Australasia. We did a survey of genetic health professionals, and few have ever had this asked of them. I am unaware of any data from other countries.

**HJ**: Your research has tracked the views of hearing children of deaf adults toward this practice. Their attitudes are apparently similar to those of deaf adults; they don’t seem to have a preference toward choosing deafness or not, they commonly see being deaf as a culture and not a disability, and so on. Did that surprise you given that they have the ability to hear and know what they would have missed had they been deaf?

Mr. Delatycki: It did not surprise me. We were interested in the views of this group because they know what it’s like to be able to hear, but among people who can hear, they understand best the issues faced by deaf individuals and the deaf culture. As a group, half viewed deafness as a disability as well as a distinct culture. About one-third wished at some point in their lives that they were deaf, but none indicated that they would have preferred to be deaf at the time they completed the survey as adults.

**HJ**: What is the general attitude of genetic professionals toward selecting for deafness?

Mr. Delatycki: I don’t know the answer to this. I don’t believe there are published data. I do know from talking to colleagues that some strongly feel that parents should be able to choose to take steps to select a deaf child and others who feel equally strongly that the opposite approach is appropriate.

**HJ**: What is the ethical debate surrounding this choice?

Mr. Delatycki: I think it is framed in terms of the parents’ right to choose the sorts of children they have, the question of whether deafness is a disability and a culture, and the obligations of health professionals toward potential offspring of people who make these requests.

**HJ**: Some have compared deaf parents choosing to have a deaf child with the choice of hearing parents fitting their deaf child with cochlear implants or hearing aids. Is this a valid comparison?

Mr. Delatycki: I understand the comparison in that if deaf parents take steps to ensure their child is deaf, the child has one unique experience — growing up in the deaf culture — but misses another — hearing —, and by fitting the child with cochlear implants or hearing aids, the opposite is true. I believe the issue is how one weighs the value of those two experiences. My view, perhaps biased by the ability to hear and my limited exposure to the deaf community, is that the ability to hear opens more opportunities in life than being part of the deaf community.

“[The ethical debate] is framed in terms of whether deafness is a disability and a culture....”

Martin Delatycki

**HJ**: How would you as a geneticist counsel parents in this situation?

Mr. Delatycki: In Victoria, Australia, it is illegal to use preimplantation diagnosis to select for a disability. I doubt selection for deafness would be permitted by the Infertility Treatment Authority that decides who can and can’t use preimplantation diagnosis. Putting law to the side, I think that an individual has more opportunities in life if he can hear and that deliberately taking action to ensure [against that] is not something I am comfortable facilitating. I respect, however, that many disagree with this view.

**HJ**: What would you say to hearing healthcare professionals who might be troubled by people making this choice?

Mr. Delatycki: I respect both points of view. Health professionals often have differing ethical viewpoints on situations. A health professional needs to weigh all sides of a debate and reach his own conclusion. I would ensure the individual has access to all the information necessary to make up his own mind on this issue.

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