Employing genetic diagnosis to avoid having a baby with a disability is controversial enough. But a minority of deaf people would consider testing to ensure that they had a deaf child. Carina Dennis finds out why.

John and Karen — not their real names — are both deaf, and desperately wanted a deaf baby. But genetic testing showed that this was extremely unlikely. “They were devastated,” recalls Arti Pandya, a clinical geneticist at Virginia Commonwealth University in Richmond, who counselled the couple. It was two years before they got over their disappointment and started trying to conceive their first child.

The couple’s attitude will shock many people. If you can hear, it’s hard to understand why anyone would want a deaf child. But John and Karen’s views are not that unusual among those who identify themselves as ‘Deaf’ with a capital ‘D’. The Deaf view their condition not as a disability, but rather as the underpinning of a rich culture that should be celebrated and preserved. And with the identification of the most common genetic mutations linked to deafness, it is now possible, in theory, to make an active choice to have a deaf child.

This possibility turns the debate over designer babies on its head, providing ethicists and genetic counsellors with a dilemma. Only a tiny minority of deaf people would wish to use genetic tests in this way. Some argue that their reproductive choices should be respected. But is society prepared to sanction the use of genetic diagnosis for a purpose that many find difficult to understand — and some might even see as immoral?

Some Deaf people despair of ever being understood by those who aren’t part of their culture. The Deaf identity is in large part a product of a shared sense of isolation from the hearing world. “Exclusion is central to the experience,” says Gary Kerridge, regional disability liaison officer at the University of Ballarat in Mount Helen, Australia, who lost his hearing as a young child.

For deaf children, the majority of whom are born to hearing parents, even family gatherings can be lonely affairs. Many of them feel liberated by their first experience of Deaf culture. “They learn to sign and suddenly for the first time, after years of being isolated and struggling, they are accepted,” says Kerridge. “Naturally, they quickly develop a strong attachment to the Deaf way of life.”

A world of their own
Sign language is central to the lifestyle. It uses hand shape, position and movement, plus posture, facial expressions and other visual cues, to form words and convey meaning. It has its own rules for grammar, punctuation and sentence order. It is elaborate and expressive, and lends itself readily to poetry and theatre.

For a hearing person, entering a room full of chattering signers can be disorienting. Methods used to attract attention, for example, seem downright rude. “Stomping on floors, waving animatedly, flashing lights and thumping tables are all considered OK,” says Kerridge.

Knowing sign language doesn’t, by itself, break down the barriers between the hearing and the Deaf. “Even hearing people from Deaf families and who sign well are always, to a certain degree, seen as culturally distinct,” says Kerridge. “That absolute feeling of exclusion from the hearing world is difficult for a hearing person to fathom.”

Within Deaf culture, however, there’s a level of social intimacy that is rare among the hearing. “I will meet another Deaf person for the first time and in five or ten minutes, it’s not uncommon to know a great deal about their family and personal life,” says Carol Padden, a linguist at the University of California, San Diego, who was born deaf, to deaf parents. “I have to remind myself not to expect the same invitation to become familiar when I’m with hearing colleagues.”

That, in a nutshell, is why some deaf couples would prefer to have deaf children. Communication and the pursuit of intimacy are central to being human. If you genuinely believe that your children will have at least as rich an emotional life if they cannot hear, and...
Tough choices

Middleton says that it’s still unclear what people would do when faced with the choice for real. “Attitudes do not necessarily predict behaviour,” she cautions. And even among Deaf activists, it’s hard to find someone who will be quoted as saying they would abort a hearing fetus, because of the opprobrium they would attract. “Deaf people know that it’s a very risky thing to say in public that you would consider genetic testing to have a deaf child,” says Padden.

The wisdom of keeping quiet was reinforced by the controversy that engulfed Sharon Duchesneau and Candace McCallough in April 2002. A deaf lesbian couple from Bethesda, Maryland, Duchesneau and McCallough told the Washington Post Magazine that they had conceived a child using sperm donated by a deaf male friend, because they wanted a deaf baby. They didn’t employ genetic testing to guarantee success, but their son, Gauvin, was born deaf. While the initial article was sympathetic, many of those that followed were not. The Fox News website, for instance, ran a hostile piece, headlined “Victims from birth: engineering defects in helpless children crosses the line.”

Deaf couples wanting to be sure of having a deaf child have two options. They could use prenatal genetic testing, and abort the fetus if it can hear. Or they could consider aborting a fetus if it would turn out to be a hearing one. Evidence that a small minority of deaf people would consider this option comes from the work of Anna Middleton, a genetic counsellor at Addenbrooke’s Hospital in Cambridge, UK.

Middleton’s first survey was conducted at the Deaf World conference, a gathering of the culturally Deaf held in Preston in northwest England in 1997. Of the 87 delegates who completed the questionnaire, 14 said they would consider prenatal testing for deafness. Four of these said that they would prefer to have deaf children.

Middleton’s second survey was carried out late last year with a culturally Deaf couple hoping for a deaf child to use the test. The Infertility Treatment Authority for the state of Victoria, which sanctioned the Monash procedure, says it would not allow a couple wanting to exclude the one-in-four chance that they would have a deaf baby.

The Infertility Treatment Authority for the state of Victoria, which sanctioned the Monash procedure, says it would not allow a couple hoping for a deaf child to use the test. ‘Our policy states that the procedure should be used to avoid a genetic abnormality,’ says Helen Szoke, the authority’s chief executive. Few other regulatory bodies have yet devised
news feature

Handmade: the Café Signes in Paris is designed to bring locals and the deaf community together.

mutations that can cause deafness.

For many people born deaf, including Padden, the attitudes revealed in the piece struck close to home. "That article sent chills down my spine," she says. Middleton's surveys suggest that many deaf people feel similarly. The culturally Deaf, in particular, feel threatened by the possibility of genetic diagnosis leading to the abortion of deaf fetuses. Some postings on deaf online forums have equated genetic testing with Nazi-style eugenics. Similar attitudes underpin widespread Deaf opposition to the idea of 'curing' deaf people using cochlear implants.

Testing times

This unease may explain why Middleton's surveys have shown that deaf people are less likely than the hearing to consider prenatal testing for deafness. And among those who would consider testing, opinions vary widely. Many deaf people, for instance, are appalled by the idea of aborting a fetus if it can hear. Opinions may depend in part on whether the individual was born deaf or lost their hearing later on, and whether they grew up in a deaf family.

Given these diverse viewpoints, some experts argue that it's unfair to focus on the minority of the culturally Deaf who say they would consider aborting a hearing fetus. It is offensive to keep harping on about this scenario. While many deaf parents may harbour a preference for having deaf children, the data suggest that the majority would never consider doing it," says Barbara Biesecker, a genetic counsellor at the National Human Genome Research Institute in Bethesda.

But if genetic testing to screen against deafness takes off, and the Deaf feel that their culture is threatened, it's possible that some will want to fight back. In this case, their best option might be to adopt the very technology they fear, and embrace genetic testing to ensure that they have deaf children.

It's even possible that some may have already done so, without anyone realizing. In many countries, there are no legal obstacles to stop a woman obtaining a prenatal test for deafness, without revealing her true motivations, and then seeking an abortion from a different healthcare provider if the result showed that she was carrying a hearing fetus. “If the question is whether there are any restraints to prevent somebody from doing this, the answer is no,” says Biesecker.

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