

NEWS

Controversy over deliberate conception of deaf child

In a decision that has provoked vigorous response from ethicists, conservative groups, and the deaf community, a deaf lesbian couple in Bethesda, MD, USA, have chosen to have a deaf baby through artificial insemination with a deaf donor.

The couple, Sharon Duchesneau and Candace McCullough, contacted a sperm bank to ask for a deaf donor. But since congenital deafness is a contraindication to donation, a deaf friend, who is also the father of the couple's 5-year-old daughter, became the donor instead.

The baby, a boy named Gauvin, was born in November, 2001. His hearing loss has recently been confirmed. Audiologist Peggy Nelson (University of Minnesota, Minneapolis) said that two screening tests are normally done in infants—the first, otoacoustic emissions, within hours of birth. This test requires no cooperation from the infant and simply establishes the presence or absence of hearing.

The second test, auditory brainstem testing, is slightly more invasive, requiring a sleeping infant and the placement of a number of scalp electrodes. Sounds are transmitted through each ear independently, and brain responses provide an estimate of hearing thresholds. This test can also be done on the first day of life. Behavioural testing, however, which is the gold standard, is not done until around 6 months of age. It requires an infant who can sit up and who can be conditioned to respond to sounds by turning its head toward them.

Although hearing aids can be fitted within the first few weeks of life, many deaf children do not receive them until much later; after age 5, the success rate for adaptation dramatically decreases. "We know that kids who go for years without hearing don't adapt to sound as well as children who start using their residual hearing early", Nelson said. The baby's parents say if their son wants a hearing aid later, they will let him

have one, but they do not plan to have one fitted now.

In an email interview with *The Lancet*, Duchesneau and McCullough said their decision "was a personal one, not an attempt to make a political statement about deaf culture". The politics to which they

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Duchesneau, McCullough, and family

refer are situated in a long-standing debate among, as they are sometimes known, "capital D Deaf" people, who argue against the view of deafness as a disability. Rather, according to Phil Aiello, a deaf man with a cochlear implant who works as a disability specialist (TCS Associates, Wheaton, MD), they see themselves as belonging to a "beautiful culture", one with its own history and language. Many feel strongly that they belong to a tightly knit linguistic minority, not to a group of disabled people. The routine use of cochlear implants and those health professionals who believe deaf people need to be "fixed", they argue, are stamping out their culture. Medicine doesn't get all the blame: Aiello noted that "it is the media who often have and still portray deaf people as abnormal, inferior, needing to be fixed in order to be successful in life".

The couple highlighted some of these tensions when asked about the ethics of their decision: "Most of the ethical issues that have been raised in regard to our story", they wrote,

"centre on the idea that being deaf is a negative thing. From there, people surmise that it is unethical to want to create deaf children, who are, in their view, disabled. Our view, on the other hand, is that being deaf is a positive thing, with many wonderful aspects. We don't view being deaf along the same lines as being blind or mentally retarded; we see it as paralleling being Jewish or black or a member of any minority group. We don't see members of those minority groups wanting to 'eliminate' themselves."

Current practices in reproductive medicine allow prospective parents to screen for abnormalities and select for desirable traits in their babies, such as preferred sex. But bioethicist Arthur Caplan (University of Pennsylvania, PA) distinguishes this case from these trends. Deafness does not have to be a disability, he said, but it is clearly a dysfunction, and "sex selection is not picking a dysfunction". Furthermore, the case does not have the same moral features as screening for diseases such as Fanconi anaemia, he said, because "disease avoidance is clearly ethically defensible". Caplan is critical of this couple's decision because it took away the child's choice, imposing on him "functional limits".

Duchesneau and McCullough argue that wanting a child that is like his parents is not unusual: "Had we been a straight couple, our genetic backgrounds related to deafness probably would have given us the same chance of having a deaf child as our selecting our particular donor did. Like many couples, we chose a donor who is similar to one of us, who reflected what we see as positive qualities. Many deaf people marry other deaf people and have deaf children, for the same reasons we did."

Disability, dysfunction, or simple difference? As this case makes abundantly clear, the debate continues.

Faith McLellan

The Washington Post/Andrea Bruce Woodall