

A Deaf Couple & Selective Abortion Based on a Genetic Test

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Case Narrative



You have been the pastor at a church where Roger and Sally and have been members for three years. They are deaf and the parents of one child, aged two, who is also deaf. Because your church has used sign language to interpret sermons and adult education classes for many years, your parish has many deaf people in the congregation.

Sally has just found out she is pregnant. They are happy about this development but are concerned about the likelihood that their next child will be deaf also. You have just attended a continuing education conference on genetic testing and know there are tests that screen for many genetic disorders that cause deafness. They have come to you for counseling. You tell Roger and Sally about some of the genetic testing options and give them a business card of a clinic that can do this screening. As they tell you their story you suddenly realize that they were not worried about having a DEAF child, but a Hearing child... They want to screen for and selectively abort any fetus which WILL be able to hear. In other words they have decided they want a deaf child and are willing to go through an abortion if their fetus does not have one of the alleles that lead to deafness.

You are quite stunned by this unexpected exchange and wonder about your role in providing the means for this couple to selectively abort a healthy fetus.

Questions

1. Think about the larger issue of selective abortions based on a single trait or set of traits. What is the message to the disabled community? (A blind bioethicist, Adrienne Asch, has argued that all prenatal screenings should be banned based on its implications for the community of disabled persons.)
2. Notice the way we tend to use words like “disease,” “disorder,” “condition,” “disability” and “trait” when referring to different sorts of genetically produced somatic outcomes. Is deafness a disease? A disorder? A condition? A disability? A trait? A “culture?”
3. If we allow people to selectively abort to insure a “healthy” child does this imply we should allow people to selectively abort to insure a “disabled” child?
4. One person is left out of the loop in this scenario. The child who will be born deaf. The more knowledge and control we have over reproductive outcomes the

more significant the questions become concerning the rights of the person most affected by these decisions.

5. What sort of regulation should be in place, if any, with respect to selective abortion based on a single trait or set of traits?
6. Would you respond differently if the couple were *blind*?

