

## GENETIC COUNSELING

People at risk for or suffering from hereditary diseases can choose to talk to *genetic counselors* regarding the nature of their disorder as well as options available in family planning. The job of such counselors is not to tell people what to do but rather to state the facts and options in an as *neutral* manner as possible so that the patient can make an *informed* decision.

This makes a lot of sense, if we consider the ways in which such counseling *could* go wrong:

- Dogmatic recommendations of any particular option—e.g., regarding the termination of abortions involving fetuses with severe genetic diseases—on part of the counselor could be construed as falling within the tradition of *eugenics*.
- In general, a too enthusiastic espousal of abortion as an option in cases of genetically disabled fetuses may be construed as “*abortionist*,” and, as such, politically controversial.
- A too substantial role of counselors in genetic decisions would involve outsourcing to a third party decisions associated with family planning that are intensely *private*.

Consequently, the primary principle guiding genetic counselors in their work is something like the following:

*Respect the patient's autonomy—including their particular beliefs, cultural traditions, inclinations, circumstances and feelings—and strive simply for enabling the patient to make informed and independent decisions.*

This all sounds well and good—until there is a moral conflict between the patient’s autonomy and other factors we deem morally relevant. Take, for example, the case of deaf parents wanting a deaf child. It is one thing for a counselor to not intervene when parents deaf due to hereditary factors want to have children; it’s quite another, it seems, when they want help with selecting a child suffering from what we tend to think of as a *disability*.

## OPEN FUTURES

So how are we to think of the considerations that may be brought to bear on this kind of situation? Davis wants us to understand the relevant considerations in terms of a parental responsibility to not rob the child of an *open future*. What does this mean? We can imagine that rights come in four kinds:

- *General rights*. Such as the right not to be killed (shared by children and adults).
- *Dependency-rights*. Such as the child’s right to food, shelter, and protection.
- *Adult rights*. Such as the free exercise of religion.
- *Rights-in-trust*. Such as the right of a child to not have her future options be radically restricted by parents.

Here are two concrete examples of rights-in-trust:

- (a) *The right to reproduce*. It might be that, as a child, you don’t have a right (or even ability) to reproduce. Still, this does not make it OK for the parents of a child to sterilize her at a young age, thereby making it impossible for her to ever conceive.
- (b) *The (general) right to an open future*. There are tons of things that you cannot do or experience as a child. Still, that does not mean that it is right for the parents of a child to, say, restrict your education in ways that will virtually ensure that you will become a housewife or an agricultural laborer.

The latter issue has been discussed in relation to the Supreme Court decision to allow Amish parents to not send their children to school past eight grade, since doing so would be antithetical to their (i.e., the parent's) religion and way of life. Dena Davis suggests that this decision fails to take into account the rights of the children involved, and defends the following principle:

*A liberal state must tolerate even those communities, like the Amish, most unsympathetic to the liberal value of individual choice, but at the same time safeguard the ability of the individuals to shift allegiances and cross boundaries.*

As she puts it: The autonomy of the *individual* is prior to that of the group.

#### DEAF CHILDREN AND OPEN FUTURES

So how does this bear on the issue of deaf parents wanting deaf children? Here is what Davis says:

“If deafness is considered a disability, one that substantially narrows a child’s career, marriage, and cultural options in the future, then deliberately creating a deaf child counts as a moral harm. If deafness is considered a culture, as Deaf activists would have us agree, then deliberately creating a Deaf child who will have only very limited options to move outside that culture also counts as a moral harm. A decision, made before a child is even born, that confines her forever to a narrow group of people and a limited choice of career, so violates the child’s right to an open future that no genetic counseling team should acquiesce in it” (p. 254).

**Question:** Does Davis’ point apply equally in (a) the case where we are engaging in selective abortion or pre-implantation diagnosis, as in (b) a scenario where the parents have the option of providing cochlear implants for their infant?