

In this section we're going to look at what I think of as one of the very most challenging debates that's going on in bioethics, one of the ones that's hardest to think through for many of us. And that's the question of whether it's ever ethical to intentionally create a child that has a disability, whether parents ought to be allowed to go out of their way to create a child who has a disability. We're going to focus in particular on the case of deafness. It's come up for several disabilities, but that's the one where there have been the most vigorous debates.

On the face of it, you might think that's obviously not OK. One reason you might think it's obviously not OK is because it might sound to you like somebody is harming a child. But remember we talked in the last section about the paradox of harm and how you can't harm a nonexistent being. So since the child doesn't yet exist, bringing a child with a disability such as deafness into existence doesn't actually harm that child. That child will either not exist at all or they will exist as a deaf child. So the argument that we're harming a child is not a good argument. However, we might still just intuitively feel that this is just clearly wrong. But let's dig into it a little bit.

Let's step back and think a little bit about deaf culture. Deaf culture is special compared to culture around any other disability. The deaf community has a rich and well-developed set of cultural resources available to it. They have their own languages, they have their own universities, they have their own poetry, their own music, their own cultural resources, and they have in many places built a very strong community. Lots of times deaf parents care very deeply about having children who belong to that community with them, who are raised as part of that deaf community. And they believe, not unreasonably, that if their children are hearing children, that they won't be in that community, they won't have a place inside of that community. Many of us want our children to share a community with us. It's not a surprising desire.

Another really popular and common argument against the intentional creation of deaf children is the so-called Right to an Open Future argument. The idea here is that it's one of the central moral duties of parents to ensure that their child has as open of a future as possible, as wide of a range of opportunities open to them as can be managed. And to make a child deaf on purpose is to knowingly foreclose certain sorts of options, and hence it's unethical. This might seem like an obvious argument, but again, I think when we start digging into it, it turns out to be quite problematic. So for example, we let parents do all sorts of things to their children that seriously restrict their children's opportunities.

Some parents raise their children with very, very narrow religious views, for instance, or some parents raise their children in very small, remote towns without a lot of resources, where they don't have access to various educational and cultural opportunities or access to various kinds of people and possibilities that would broaden their options for when they grow up. We might or might not think that those are completely acceptable ways of raising your children, but whether or not we do, we certainly think that parents are well within their rights to raise their children in these ways, to raise them in remote areas or with restrictive religious views of their choosing.

Now deaf people, as we know and as we've discussed, can live rich and varied lives and have all sorts of community resources available to them and lots and lots of possibilities for what they can do with their life. So it's actually not at all obvious that parents who go out of their way to raise a deaf child are restricting that child's future more than other sorts of parents who make choices that we don't get in the way of.

There's a bioethicist and disability theorist named Anita Silvers who also criticized the Right to an Open Future argument in a slightly different way, through what I think is a beautiful analogy. She talks about going to a restaurant and being given a menu. And she says look, would you prefer to receive a menu that has lots and lots and lots of choices on it, but the choices aren't particularly good ones? Or would you like to receive a menu that has only a few choices on it, but the choices are excellent and delicious? It seems like our options are better in the second case than in the first. So perhaps the openness of our future that we care about shouldn't be about number of opportunities but about quality of opportunities.

If we think about it that way, you might think that deaf parents are going to be better able to advocate for their children, communicate with their children, understand their children, and give their children the kinds of opportunities that come with belonging to a home community and having resources available than they would be able to do for hearing children. And in that way, they might actually be giving their children a more open future in the relevant sense than if they raise their children to be hearing. So it's actually not clear which way the open future argument cuts.

Now I'm not either advocating or opposing the possibility of allowing the intentional creation of deaf children in this section. I really just want to complicate the issue and show that it's not nearly as straightforward as it might seem at first. And one of the main reasons why it's not as straightforward as it might have seemed is that disability and normalcy are much more textured notions, as we're starting

to see, than we might formerly have thought. And because of that, it's just not clear what counts as helping a child achieve normalcy and flourish. And in some circumstances, perhaps the best thing we can do to help a child achieve normalcy is actually to ensure that that child has a disability, as counterintuitive as that might seem.