Designing Deaf Babies and the Question of Disability

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This article explores the recent controversy surrounding a Deaf lesbian couple’s deliberate attempt at finding a Deaf donor to increase their chances of having a d/Deaf baby. Many have criticized the Deaf couple for harming their child; Deaf advocates have responded that the couple’s decision reflects a natural cultural desire. This article seeks to explore how the medical model of disability implicitly used on both sides of the debate has obscured important points. Once this controversy takes into consideration the social construction of disability, the ethical defense of seeking a deaf child gains further support. This leads to the ironic claim that seeking a deaf child could actually mitigate the conditions of disability within the family.

Suppose you find yourself shopping for sperm, leafing through a donor catalogue. What are you looking for? Eye color? Hair color? Height? Hispanic? Harvard? Cambridge? Deaf? What? Not in a sperm bank, you don’t. Donors with congenital disabilities are screened out long before they would ever make the catalog. If their sperm bank deposits had any value, it would surely be negative, for what sort of customers would make a withdrawal like that? But, what the reproductive marketplace did not anticipate is that disability affects different people in different ways, many of them unlikely to persons without disabilities. It appears that there just might be couples who desire donors who are both deaf and Deaf—that is, donors who do not hear and who come from the linguistic minority of American Sign Language (ASL) users. In this language group, deafness often carries a positive value; as a result, the genetic material of deafness just might have a market value.

In spring 2002, the Washington Post Magazine (Mundy, 2002) featured a story about a lesbian couple that deliberately searched for a Deaf sperm donor to increase their chances of having a deaf baby. The response to this article—from the popular press to the Journal of Medical Ethics (Spriggs, 2002; Levy, 2002; Anstey, 2002) from the United Kingdom to Australia—was prolific and polarized. On the one hand, many saw the parents as abusively and selfishly disabling their child. In an article in London’s Guardian newspaper the week following the Post’s story, Jeanette Winterson (2002) likened the Deaf couple to members of a radical religious sect who coerce their children into their own psychosis. Next to Winterson’s article was the response by a fourth-generation deaf woman, Sharon Ridgeway, who saw the desire for a deaf baby as unremarkable, a natural choice for couples who prefer children who share their background. One couple, one child, and a global reaction that deepened the balkanization over the d/Deaf cultural wars.

Why did the reproductive choice of a single couple ignite such fury? Perhaps because it is an assault on standards of normalcy, turning them on their head, fashioning some new mutant strain of normalcy. And, the problem with normalcy is that it is not used to such competition. As with debates over cochlear implants, the discussion over designing deaf babies posits a minority whose views run counter to a larger, wealthier
worldview and morality founded on institutionalized notions of normalcy. Indeed, as Winterson wrote, “If we are prepared to use technology to breed children we have deliberately disabled, it is not only the language of disability that will have to be radically reworked, but our entire moral perspective” (Winterson, 2002). Although Winterson cautioned against such a reworking, I believe this is the type of reworking that is long overdue. As the popular language of disability has come to us in the form of a medically arbitrated monologue, it gives way to a medically infused moral perspective. Indeed, going public with designing deafness may provide an impetus for a reworking of the ways our society currently understands the dynamics of disability, deafness, culture, and the ethics.

How, then, can the public response from Deaf and disability communities be more than damage control? How can it contribute to this larger reworking? How can it seize the issue and provide it as a public lens through which outsiders may see how someone (although not necessarily themselves) could actually desire a trait others see as disabling? How could it help us to bring into focus the question of what sorts of lives are worth living and who has the right to participate in making those decisions?

Before we engage such questions, we better be sure we know what we are looking at, for the stakes are high and the ethical issues thorny. So, let us look further into the language of disability as it circulated throughout the popular press.

Reworking the Language of Disability

To no great surprise, “designing deaf babies” magnifies radically divergent constructions of deafness, culture, and disability held within our society. On a closer look, though, it appears that both opponents and proponents of the couple’s decision share a similar medicalized model of disability. This common understanding, however, does not give way to communication; instead, neither side can understand the other amid the interference of misunderstandings of the dynamic relations among disability, culture, and identity. On the one hand, the issue of designing deaf babies has less to do with disability than opponents would assume and more to do with disability than the Deaf response would assume. The argument of this article, then, is that by reworking the language of disability from a medical to a social model, we may arrive at a more focused argument in which the Deaf position—that it is ethical to deliberately seek a deaf baby on the grounds of a shared culture—can gain greater justification. In such a reworking, both sides may end up at the same place: deafness can be a disability and deafness can be a cultural identity, not always, but often, at the same time. By laying claim to disability, the defense of designing deaf babies has the potential to contribute to the larger reworking of a moral perspective that allows for alternative and equally valid standards of normalcy.

Simple Facts

“It is a simple fact that it is better to have five senses than four.”

Jeanette Winterson

Who can argue against that? After all, it is common sense, right? Yet, what Winterson calls a “simple fact” may not be so simple or so factual for everyone. Other facts arise from those who live Deaf lives. One such fact is that many Deaf people believe that to be Deaf and Italian, or Deaf and Navajo, or Deaf and Japanese is not to be less, but more. Another such fact is that one cannot dispute that Deaf people have been choosing Deaf partners in marriage at a rate of about 90% since the 19th century; as a result, they have been giving birth to deaf children all along, forming Alexander Graham Bell’s worst fear—a deaf variety of the human race. In light of this historical fact, we may see that the lesbian couple featured in the Post’s article was only doing what lesbians who wish to give birth to their own kind would do. They chose Deaf partners for marriage and likewise Deaf donors for their children. There would still be a high chance that they would have a hearing baby, which would, in their words, “be a blessing.” It is just that “a deaf baby would be a special blessing” (Mundy, 2002). That many Deaf couples feel this way is another simple fact in the Deaf world. Different worlds, different facts. (One would also wonder how Winterson would respond to the claim that it is a simple fact that it is better to be heterosexual than homosexual.)
The opponents to their reproductive choice believe that deaf people lead more difficult lives than hearing counterparts. Indeed, it is more convenient to be hearing than deaf, but such convenience does not de facto lead to an increased value of one’s life. Presumptions about the horrors of deafness are usually made by those not living Deaf lives. Deaf lives reveal that disability affects people in different ways, and that hearing loss has catalyzed deaf persons to convene a culture with members who experience a depth of affiliation comparable to any other ethnic group and linguistic minority. Clearly, my colleagues and friends are more culturally Deaf than I am culturally Irish or German. The disability of hearing loss, then, is not such a simple fact. If it were, then those who have the most intimate knowledge of its experiences would agree with Winterson, but they largely do not: different lives, different facts.

Such recognition of the contextual nature of disability may disrupt medical language of disability from speaking through individuals, even those on the left like Winterson. Yet, the medical model is so pervasive that it speaks not only through those who oppose designing deafness, but also for those who support it.

Flashing Lights and Text Phones

In fact, it’s not a radical school of thought at all. Having a shared language (sign) means we can be part of a culture with which we can all identify. We all share the same ways of life and values—like the same technology such as flashing lights in the home and text phones, as well as common beliefs, games, humour, history and poetry. Why wouldn’t I want my daughter to be a part of that?

Sharon Ridgeway, a fourth-generation deaf woman

To such a defense, I would have to ask, but why would I want my daughter to be a part of that? Flashing lights, text phones, and Deaf games hardly seem justification for choosing deafness over hearing. Is it really culture that creates the special blessing of deafness? This is a problematic claim for it implies that the hearing child of deaf adults (CODA) cannot participate in the culture of the child’s parents. After all, if Deaf culture is founded not through hearing loss, but through a shared language and cultural practices, what is the point in having a deaf baby? In a house in which ASL is the native language, a hearing child will manually babble his or her way into using ASL as its first language, much like a Deaf child. Sharon Ridgeway seems to miss this vital point when she states that, “Finding out that my daughter was deaf just the day after her birth was absolutely delightful because it meant I could sign to her” (Ridgeway, 2002). One must ask: What would she do with a hearing child? Of course, she could sign just as much as to a hearing child as to a deaf child. Whether hearing or deaf, children raised in a Deaf family would also be exposed to the social and cultural practices of their parents. I know several CODAs who, even though they are not deaf, are clearly culturally Deaf.

So what, exactly, is the difference between having a hearing or a deaf child? What is so “special” about the special blessing of deafness?

The difference between having a deaf or a hearing baby, I contend, has less to do with culture at the onset than it does with the social, political construction of disability. If reworking the language of disability may help Winterson see that deafness is not a simple medical fact, then it may also bring into focus exactly what is so special—and more important, ethically justified—about having a deaf as opposed to a hearing baby. By laying claim to disability, two claims emerge that may ultimately enhance the defense of designing deaf babies. First, having a deaf baby in a Deaf family distances the social site in which disabling conditions are most prevalent. Such an environment then opens the space for a visually centered episteme to emerge that results in lived experiences not predicated on the lack of a sense, but on the plenitude of a visual culture with its own norms of language acquisition and identity development.

Where Is Disability? Contact Zones and the Deaf Family

In reworking the language of disability, we must also ask our questions differently. Where is disability? If it is not only (or not at all) on the body but also in the social, physical, and political environment, where does it take
place? Most Deaf people would grant that there is little disability in an all-signing environment. It is only once there is no access to communication that the conditions of disability become evident. Thus, it is only within the contact zone between hearing and deaf worlds, between auditory and visual modalities, that the conditions of disability make themselves present.1 Such contact zones may be described as “social spaces where disparate cultures meet, clash, and grapple with each other, often in highly asymmetrical relations of domination and subordination” (Pratt, 1992, p. 4).2 It is only in the hearing/deaf contact zone where the site of disability emerges. It is here that there are no text telephones, no captions, and no (or inadequate) interpreters. It is here that hearing people enjoy systems of advantage and deaf persons systems of disadvantage. It is here that we may find a partial explanation for the special blessing of having a deaf child.

As a visual minority in a phonocentric world, Deaf persons are surrounded by contact zones—at work, school, stores, and playgrounds. But, in a family in which both children and parents are Deaf, the auditory/visual contact zone does not run throughout the house. It may be right outside the door, and it may find its way in from time to time, but it does run through the dinner table. It is within this space that a deaf infant would undergo what neurolinguists consider “normal language acquisition,” only in this case it is a signed language that is acquired. It is within this space that a deaf toddler would do just about everything that a hearing toddler would. In this space, that young deaf child sees him- or herself as so “normal” that the child wonders what is wrong with those people across the street whose hands are broken and whose mouths convulse all the time. In such an environment, a child’s intellectual, spiritual, and emotional development parallels that of any hearing child. The child may not hear, that is true, but it is not a “simple fact” that the child’s life will be less for it. Thus, one aspect of the special blessing may be the very ironic situation that having a deaf baby might actually mitigate the conditions of disability within the family.

Again, it must be emphasized that Deaf parents love their hearing children just as unconditionally, but in light of reworking of the language of disability from medical fact mapped on the ear to the social space of the contact zone, we may see that a hearing child of deaf parents grows up, not near the contact zone, but within it. CODAs often find themselves perpetually grappling with both worlds—a difficult act for adults, let alone children. CODAs live their hyphenated lives in varying degrees of vacillation, ranging from those who are culturally Deaf, to those who renounce the Deaf-World and its language, culture, and members (see Preston, 1994). Whatever the relation to the Deaf-World, CODAs will have to negotiate these worlds, which can have both enriching and debilitating effects. In contrast, the Deaf child of Deaf parents will not have to embody the contact zone in exactly the same way. Compared to CODAs, Deaf of Deaf rarely escape the fold but rather embrace their identity as members of a visual and linguistic community.

Once the social model of disability enters the popular discussion on designing deafness, it leads to a very ironic or counterintuitive position: By choosing a deaf child, the family will have less contact with the conditions of disability than if they were to have a hearing child. This is not to say that Deaf of Deaf are better off than hearing of Deaf, but it is to say that they are not by necessity worse off because they cannot hear.

This view needs to be taken into account by those opponents like Winterson who have spent little time around d/Deaf children of d/Deaf parents and who claim to know what d/Deaf lives are like. Winterson concluded her article by writing that the Deaf couple “both practise as mental health specialists, so I hope they have a colleague who will be able to talk it through with two kids who turn up in 20 years, explaining that their mothers decided that they had to be deaf.” Research, however, indicates that this may not be necessary: Deaf children of Deaf adults tend to exhibit comparatively healthy self-esteem. (Bat-Chava, 2000). In such a situation, it is not always a simple fact that it is better to have five senses than four. The lives of Deaf people show us that it is not so much the number of senses a person has, but what the person does with them.

Conclusion: Counting the Special Blessings of Disability

What do Deaf people make with their four senses? They have made their own epistemological path in the
world; together, they have convened a visual culture with its own traditions, literature, and heritage, and, yes, with its flashing lights and text phones. To begin to grasp the worth of living a Deaf life is to begin the reworking of the language of disability and our entire moral perspective. Such a reworking may lead toward a more dynamic intersection between disability and culture, in which those like Winterson can see that it is not a simple fact that being hearing is better than being deaf. Deaf activists may also strengthen the cultural argument by recognizing that within the contextual nature of disability, sometimes having a deaf child is defensible on ethical, moral, and psychological grounds.

Notes

1. It is more complicated than that, for this model presupposes that there are autonomous worlds, and that the ideologies of the hearing world do not influence the very structures and objects of thought that circulate in the so-called autonomous Deaf-World. But for the purposes of this discussion, we use these terms and concepts.

2. I wish to thank Joseph Murray, for introducing the concept of the contact zone as a means of explaining deaf experiences.


References

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