

Lullabies for Sophia

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Sophia was born perfect.

I had six hours of untempered joy before the routine ALGO test, now widely used to screen newborns for hearing impairment, hinted at a serious problem. I remember staring at the ALGO computer monitor, waiting impatiently for it to register Sophia's brain response to sound. There was practically none.

The test was performed the next day with similar result. A team from Audiology came to our hospital room to explain that Sophia's failure of the screening test may not be an indication of deafness – her ears may be blocked with amniotic fluid; she may have a bacterial infection; and so on. We should come back in two weeks to have her tested again.

Sophia is deaf.

The excitement of having a new baby was entirely eclipsed by the fact that Sophia could not hear, and might not talk. While a perceived fragility drew us closer – Sophia would not be out of our embracing arms for a moment – many parental instincts were stunted. Singing lullabies felt idiotic; indeed all impulses to make sound met in my throat with sadness and anger.

I felt grief over every sound Sophia might never hear: the wind in the trees, the crashing of ocean waves, all varieties of music. Then came the concerns of

how Sophia would navigate her way in the world, how she would learn, how she would relate to others.

Decisions had to be made very early on – about whether Sophia would get hearing aids, and whether we would pursue a path of oral communication or manual communication, or both. The complexity of the decision-making process was startling. The politicization of the debate was disheartening. That I had only six hours of untempered joy was maddening.

The most striking fact in the decision-making process was the fact that I did not yet know Sophia. I had to make decisions on behalf of a person whose identity was undeclared, underdetermined, unknown and unknowable. Some people in the Deaf community suggested that her deafness itself was her identity. When I told someone that we were considering an oral approach for Sophia (then just 3 months old), he said: "Why don't you let her be who she is?" I replied: "*Who is she?*" The suggestion that Sophia's identity lies in her deafness should (I thought) meet with as much opposition as the suggestion that a person's identity is reducible merely to her race or gender. How could Sophia's deafness be who she is? Is my status as a hearer *my* identity? Surely Sophia would have more to go by.

Without a clear sense of Sophia's identity, I was yet haunted by the knowledge that whatever decisions we made would themselves contribute to shaping her identity. Though many parental decisions are like this, the decisions we had to make were not the kind that a child, with burgeoning sense of self, could later override. If we

focused exclusively on manual communication, Sophia would not learn to listen or speak; and any later efforts she might make would be fraught with difficulties of sound comprehension and production. If we focused exclusively on oral communication, Sophia might later learn to sign, but she would never be fully accepted in the Deaf community.

Here the politics of deafness felt suffocating. Couldn't Sophia straddle multiple communities? There seemed to be an intractable exclusivity on both sides of the cultural divide. If unable to speak, Sophia would be excluded from many opportunities in the hearing world. Yet, with aids and speech work, Sophia would be alienated from members of the Deaf community who frown upon attempts to "assimilate" into oral culture, such attempts being viewed as tacit admission that the inability to hear and speak is a disability to be overcome. Faced with decisions that seemed to determine her future community membership in addition to her cognitive and linguistic development, we felt overwhelmed and fraught with uncertainty. The option of total communication (speaking and signing together) was appealing, but there was reason to worry that Sophia, in trying to do both, might in the end master neither.

I thought a lot about the intimacy of sign language: that the people in conversation must be face to face, always looking at one another, in contrast to spoken language, where one can be turned away, even otherwise occupied. I pondered the beauty of its expression, and romanticized about its almost 'private' status in a world where most people don't sign. At the same time I worried that, as a non-native

signer, I would have to recede from Sophia's life. We might even need an interpreter to communicate with each other. (Why assume that my proficiency at sign language would surpass my bare proficiency at any other second language? I imagined how it would be if I could only communicate with Sophia in my meager Italian – a disaster.) Even if I could master basic sign language, how could I describe the world, my feelings, my thoughts to Sophia in all of their complexity? I feared that my communication, and so my intimacy, with Sophia would be blunted, cut short, incomplete. As most parents could, I could not be my baby's primary teacher about the wonders of the world.

Sophia got her first hearing aids at three months old. They were huge. I remember thinking that Sophia looked like a bejeweled African Queen, wearing long, dangling earrings. We found ourselves doing what people commonly do in proximity to elderly hearing aid wearers: talking VERY LOUDLY. As it turns out, Sophia's hearing aids, digitally programmed with great precision to the exact contours of her audiogram, amplified what she couldn't hear, left unchanged what she could, and ultimately enabled her to hear a whisper.

Insurance wouldn't cover the enormous expense of the hearing aids: Sophia's congenital deafness was a "pre-existing condition." As a philosophy professor, I was stumped. (What, exactly, did the condition pre-exist? If I could show that Sophia existed (as an insurable entity) before she was deaf (say, in the first few months *in utero*) would they cover the hearing aids?) As a mother of a deaf baby, I was mortified. Sophia's first pair of hearing aids cost \$4,000; and we

would have to consider whether an additional FM system, for \$3,000, might later be necessary. The blanket refusal to cover the cost of hearing aids saved insurance companies from the onslaught of elderly hearing aid users. The fact that newborn babies require access to sound in order to acquire spoken language was lost under the blanket. We were lucky to have generous families.

Sophia is two years old now, and she is talking up a storm. She is a more attentive listener than her hearing parents, and she promises to be a more articulate speaker. Most people tout her as a winning example of early “intervention” – set with hearing aids before six months, many hearing impaired children can develop spoken language close to or at peer level. The technologies and educational strategies are awe-inspiring. Sophia’s successes in learning spoken language make us feel like we made the right decision for her. Who knows if she will agree with our decision when she is older.

I have had two years, too, to sit with my mixed feelings about the cursed blessing of newborn screening. At once the grateful beneficiary of information that has enabled Sophia to hear and speak without delay, yet left longing for the untempered joy of new motherhood, I can’t help wishing, still, that I had had just a bit more time unravaged by the news, more than the meager six hours; time for singing lullabies to Sophia, without worrying about whether or not she could hear them.