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we have on campus who have disabilities, hidden or otherwise, I think, the better it is for the community. There's a little more sensitivity out there. And that's like with any of the other movements we've had. The best way to improve understanding is to improve interaction."

Among all the competing demands for attention by student minority groups, there is a tendency to think that efforts to level the playing field for one group will somehow interfere with similar efforts for other groups. But why? Haven't we learned that the inclusion of one group does not require the exclusion of another? Over the last two decades we all have seen increasing access to higher education for a growing number of minority groups. What has kept us from including students with disabilities in that access—and from recognizing how they contribute to our community? Let's face it: sometimes we're held back by fear and repulsion, more often by simple embarrassment and ignorance, and sometimes by the desire to spend our allotted funding on another program affecting a greater number of students. We should be encouraged by the parallel experiences between disabled students and other minority groups. It's time to stop telling them who they are or aren't and instead simply listen.

As a society, we are ready. After the experience of making this video, I'm convinced that attitudes about disability really have changed over the past two decades. Rachel's initiating question—whether students with disabilities were part of diversity—has been answered with a resounding yes, at least on our campus. For there was no doubt here at the University of Michigan that students with disabilities contribute to the wealth of experience that so enriches the quality of education we provide. The response to the completed video program, *And You Can Quote Me on That: Students with Disabilities at the University of Michigan*, has been striking and powerful. I had expected an audience of perhaps one hundred at the most for the premiere in September. More than twice that number came that night; every inch of the room was occupied, and people were waiting in the hallway. Following

the screening six of the students who were featured took questions from the audience. For an hour the questions came—questions that focused not on the disabled as some foreign group but as a part of the community unfairly excluded. The next day my e-mail in box was flooded with requests from faculty, students, and staff for copies of the tape. The requests continue to come in, because of the full coverage the premiere received in the student and staff newspapers and the word of mouth that promotes its value.

I don't know what the next step is, but we're ready.

## DISCUSSION QUESTIONS

1. In your college experience, has disability been treated as part of campus diversity?
2. What consequences might follow from explicitly including disability as part of a college's discussion of diversity?
3. Comparing the experience of disabled students with students of color and gay and lesbian students, what do you think are the similarities and differences in their college experience?

## READING 23

### A World of Their Own

Liza Mundy

As her baby begins to emerge after a day of labor, Sharon Duchesneau has a question for the midwife who is attending the birth. Asking it is not the easiest thing, just now. Sharon is deaf, and communicates using American Sign Language, and the combination of intense pain and the position she has sought to ease it—kneeling, resting her weight

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on her hands—makes signing somewhat hard. Even so, Sharon manages to sign something to Risa Shaw, a hearing friend who is present to interpret for the birth, which is taking place in a softly lit bedroom of Sharon's North Bethesda home.

"Sharon wants to know what color hair you see," Risa says to the midwife.

The midwife cannot tell because the baby is not—quite—visible. He bulges outward during contractions, then recedes when the contraction fades. But now comes another contraction and a scream from Sharon, and the midwife and her assistant call for Sharon to keep pushing but to keep it steady and controlled. They are accustomed to using their voices as a way of guiding women through this last excruciating phase; since Sharon can't hear them, all they can hope is that she doesn't close her eyes.

"Push through the pain!" shouts the midwife.

"Little bit!" shouts her assistant, as Risa frantically signs.

And suddenly the baby is out. One minute the baby wasn't here and now the baby is, hair brown, eyes blue, face gray with waxy vernix, body pulsing with life and vigor. A boy. "Is he okay?" signs Sharon, and the answer, to all appearances, is a resounding yes. There are the toes, the toenails, the fingers, the hands, the eyes, the eyelashes, the exquisite little-old-man's face, contorted in classic newborn outrage. The midwife lays the baby on Sharon and he bleats and hiccups and nuzzles her skin, the instinct to breast-feed strong.

"Did he cry?" signs Sharon, and the women say no, he cried remarkably little.

"His face looks smushed," Sharon signs, regarding him tenderly.

"It'll straighten out," says the midwife.

Presently the midwife takes the baby and performs the Apgar, the standard test of a newborn's condition, from which he emerges with an impressive score of nine out of a possible 10. "He's very calm," she notes as she weighs him (6 pounds 5 ounces), then lays him out to measure head and chest and length. She bicycles his legs to check the flexibility of his hips; examines his testicles to

make sure they are descended; feels his vertebrae for gaps.

All in all, she pronounces the baby splendid. "Look how strong he is!" she says, pulling him gently up from the bed by his arms. Which means that it is, finally, possible to relax and savor his arrival. Everyone takes turns holding him: Sharon; her longtime partner, Candace McCullough, who is also deaf, and will be the boy's adoptive mother; their good friend Jan DeLap, also deaf; Risa Shaw and another hearing friend, Juniper Sussman. Candy and Sharon's five-year-old daughter, Jehanne, is brought in to admire him, but she is fast asleep and comically refuses to awaken, even when laid on the bed and prodded. Amid the oohing and aahing someone puts a cap on the baby; somebody else swaddles him in a blanket; somebody else brings a plate of turkey and stuffing for Sharon, who hasn't eaten on a day that's dedicated to feasting. Conceived by artificial insemination 38 weeks ago, this boy, Gauvin Hughes McCullough, has arrived two weeks ahead of schedule, on Thanksgiving Day.

"A turkey baby," signs Sharon, who is lying back against a bank of pillows, her dark thick hair spread against the light gray pillowcases.

"A turkey baster baby," jokes Candy, lying next to her.

"A perfect baby," says the midwife.

"A perfect baby," says the midwife's assistant.

But there is perfect and there is perfect. There is no way to know, yet, whether Gauvin Hughes McCullough is perfect in the specific way that Sharon and Candy would like him to be. Until he is old enough, two or three months from now, for a sophisticated audiology test, the women cannot be sure whether Gauvin is—as they hope—deaf.

Several months before his birth, Sharon and Candy—both stylish and independent women in their mid-thirties, both college graduates, both holders of graduate degrees from Gallaudet University, both professionals in the mental health field—sat in their kitchen trying to envision life if their son turned out not to be deaf. It was something they had

a hard time getting their minds around. When they were looking for a donor to inseminate Sharon, one thing they knew was that they wanted a deaf donor. So they contacted a local sperm bank and asked whether the bank would provide one. The sperm bank said no; congenital deafness is precisely the sort of condition that, in the world of commercial reproductive technology, gets a would-be donor eliminated.

So Sharon and Candy asked a deaf friend to be the donor, and he agreed.

Though they have gone to all this trouble, Candy and Sharon take issue with the suggestion that they are “trying” to have a deaf baby. To put it this way, they worry, implies that they will not love their son if he can hear. And, they insist, they will. As Sharon puts it: “A hearing baby would be a blessing. A deaf baby would be a special blessing.”

As Candy puts it: “I would say that we wanted to increase our chances of having a baby who is deaf.”

It may seem a shocking undertaking: two parents trying to screen in a quality, deafness, at a time when many parents are using genetic testing to screen out as many disorders as science will permit. Down’s syndrome, cystic fibrosis, early-onset Alzheimer’s—every day, it seems, there’s news of yet another disorder that can be detected before birth and eliminated by abortion, manipulation of the embryo or, in the case of in vitro fertilization, destruction of an embryo. Though most deafness cannot be identified or treated in this way, it seems safe to say that when or if it can, many parents would seek to eliminate a disability that affects one out of 1,000 Americans.

As for actively trying to build a deaf baby. “I think all of us recognize that deaf children can have perfectly wonderful lives,” says R. Alta Charo, a professor of law and bioethics at the University of Wisconsin. “The question is whether the parents have violated the sacred duty of parenthood, which is to maximize to some reasonable degree the advantages available to their children. I’m loath to say it, but I think it’s a shame to set limits on a child’s potential.”

In the deaf community, however, the arrival of a deaf baby has never evoked the feelings that it does

among the hearing. To be sure, there are many deaf parents who feel their children will have an easier life if they are born hearing. “I know that my parents were disappointed that I was deaf, along with my brother, and I know I felt, just for a fleeting second, bad that my children were deaf,” says Nancy Rarus, a staff member at the National Association of the Deaf. Emphasizing that she is speaking personally and not on behalf of the association, she adds, “I’m a social animal, and it’s very difficult for me to talk to my neighbors. I wish I could walk up to somebody and ask for information. I’ve had a lot of arguments in the deaf community about that. People talk about ‘The sky’s the limit,’ but being deaf prevents you from getting there. You don’t have as many choices.”

“I can’t understand,” she says, “why anybody would want to bring a disabled child into the world.”

Then again, Rarus points out, “there are many, many deaf people who specifically want deaf kids.” This is true particularly now, particularly in Washington, home to Gallaudet, the world’s only liberal arts university for the deaf, and the lively deaf intelligentsia it has nurtured. Since the 1980s, many members of the deaf community have been galvanized by the idea that deafness is not a medical disability, but a cultural identity. They call themselves Deaf, with a capital D, a community whose defining and unifying quality is American Sign Language (ASL), a fluent, sophisticated language that enables deaf people to communicate fully, essentially liberating them—when they are among signers—from one of the most disabling aspects of being deaf. Sharon and Candy share the fundamental view of this Deaf camp; they see deafness as an identity, not a medical affliction that needs to be fixed. Their effort—to have a baby who belongs to what they see as their minority group—is a natural outcome of the pride and self-acceptance the Deaf movement has brought to so many. It also would seem to put them at odds with the direction of reproductive technology in general, striving as it does for a more perfect normalcy.

But the interesting thing is—if one accepts their worldview, that a deaf baby could be desirable to

some parents—Sharon and Candy are squarely part of a broader trend in artificial reproduction. Because, at the same time that many would-be parents are screening out qualities they don't want, many are also selecting for qualities they do want. And in many cases, the aim is to produce not so much a superior baby as a specific baby. A white baby. A black baby. A boy. A girl. Or a baby that's been even more minutely imagined. Would-be parents can go on many fertility clinic Web sites and type in preferences for a sperm donor's weight, height, eye color, race, ancestry, complexion, hair color, even hair texture.

"In most cases," says Sean Tipton, spokesman for the American Society of Reproductive Medicine, "what the couples are interested in is someone who physically looks like them." In this sense Candy and Sharon are like many parents, hoping for a child who will be in their own image.

And yet, while deafness may be a culture, in this country it is also an official disability, recognized under the Americans with Disabilities Act. What about the obligation of parents to see that their child has a better life than they did?

Then again, what does a better life mean? Does it mean choosing a hearing donor so your baby, unlike you, might grow up hearing?

Does it mean giving birth to a deaf child, and raising it in a better environment than the one you experienced?

What if you believe you can be a better parent to a deaf child than to a hearing one?

"It would be nice to have a deaf child who is the same as us. I think that would be a wonderful experience. You know, if we can have that chance, why not take it?"

This is Sharon, seven months pregnant, dressed in black pants and a stretchy black shirt, sitting at their kitchen table on a sunny fall afternoon, Candy beside her. Jehanne, their daughter, who is also deaf, and was conceived with the same donor they've used this time, is at school. The family has been doing a lot of nesting in anticipation of the baby's arrival. The kitchen has been renovated, the backyard landscaped. Soon the women plan to rig

a system in which the lights in the house will blink one rhythm if the TTY—the telephonic device that deaf people type into—is ringing; another rhythm when the front doorbell rings; another for the side door. They already have a light in the bedroom that will go on when the baby cries.

In one way, it's hard for Sharon and Candy to articulate why they want to increase their chances of having a deaf child. Because they don't view deafness as a disability, they don't see themselves as bringing a disabled child into the world. Rather, they see themselves as bringing a different sort of normal child into the world. Why not bring a deaf child into the world? What, exactly, is the problem? In their minds, they are no different from parents who try to have a girl. After all, girls can be discriminated against. Same with deaf people. Sharon and Candy have faced obstacles, but they've survived. More than that, they've prevailed to become productive, self-supporting professionals. "Some people look at it like, 'Oh my gosh, you shouldn't have a child who has a disability,'" signs Candy. "But, you know, black people have harder lives. Why shouldn't parents be able to go ahead and pick a black donor if that's what they want? They should have that option. They can feel related to that culture, bonded with that culture."

The words "bond" and "culture" say a lot; in effect, Sharon and Candy are a little like immigrant parents who, with a huge and dominant and somewhat alien culture just outside their door, want to ensure that their children will share their heritage, their culture, their life experience. If they are deaf and have a hearing child, that child will move in a world where the women cannot fully follow. For this reason they believe they can be better parents to a deaf child, if being a better parent means being better able to talk to your child, understand your child's emotions, guide your child's development, pay attention to your child's friendships. "If we have a hearing child and he visits a hearing friend, we'll be like, 'Who is the family?'" says Candy. "In the deaf community, if you don't know a family, you ask around. You get references. But with hearing families, we would have no idea."

They understand that hearing people may find this hard to accept. It would be odd, they agree, if a hearing parent preferred to have a deaf child. And if they themselves—valuing sight—were to have a blind child, well then, Candy acknowledges, they would probably try to have it fixed, if they could, like hearing parents who attempt to restore their child's hearing with cochlear implants. "I want to be the same as my child," says Candy. "I want the baby to enjoy what we enjoy."

Which is not to say that they aren't open to a hearing child. A hearing child would make life rich and interesting. It's just hard, before the fact, to know what it would be like. "He'd be the only hearing member of the family," Sharon points out, laughing. "Other than the cats." . . .

Candy usually signs with both hands, using facial expressions as well as signs. This is all part of ASL, a physical language that encompasses the whole body, from fingers to arms to eyebrows, and is noisy, too: There is lots of clapping and slapping in ASL, and in a really great conversation, it's always possible to knock your own eyeglasses off.

When she drives, though, Candy also signs one-handed, keeping the other hand on the wheel. Chatting with Sharon, she maneuvers her Volvo through Bethesda traffic and onto I-270, making her way north toward Frederick, home to the Maryland School for the Deaf. State residential schools have played a huge role in the development of America's deaf community. Historically, deaf children often left their homes as young as five and grew up in dorms with other deaf kids. This sometimes isolated them from their families but helped to create an intense sense of fellowship among the deaf population, a group that, though geographically spread out, is essentially a tribe, a small town, a family itself.

Now that people are more mobile, families with deaf children often relocate near a residential school for the deaf, where the young children are more likely to be day students. Jehanne is one; today she's waiting for them in a low corridor inside the elementary school building at MSD, petite, elfin, dimpled, with tousled brown hair and light brown, almost amber eyes. Essentially, the baby

Sharon is carrying represents a second effort that they're making because the first was so successful. (Candy tried to have their second child, but a year of efforts didn't take.) At her own infant audiology test, Jehanne was diagnosed as profoundly deaf. In their baby book, under the section marked "first hearing test," Candy wrote, happily, "Oct. 11, 1996—no response at 95 decibels—DEAF!"

This afternoon, Jehanne greets her mothers and begins immediately to sign. She has been signed to since birth and, unlike her mothers, has been educated from the start in sign. At five she is beginning to read English quite well; when they're riding in the car, she'll notice funny shop names, like Food Lion and For Eyes. But she is also fluent in ASL, more fluent even than Sharon.

The women have arrived to visit Jehanne's kindergarten classroom, which in most ways is similar to that of any other Maryland public school; the kids are using flashcards to learn about opposites, conducting experiments to explore concepts like wet and dry, light and heavy. The classes are small, and teachers are mostly deaf, which is something new; years ago, even at MSD, deaf people weren't permitted to teach the young kids, because it was believed that sign would interfere with their learning to read. Now that's all changed. Sign is used to teach them reading. They learn science in sign; they sign while doing puzzles, or gluing and pasting, or coloring, or working in the computer lab.

There is a speech therapy class, but it's optional, and a far cry from the ones that Sharon and Candy remember, where laborious hours were spent blowing on feathers to see the difference between a "b" and a "p." In general, Sharon and Candy have tried not to make what they see as the mistakes their own parents did. Sharon, for example, resents having been made to wear hearing aids and denied the opportunity to learn sign, while Candy—who really wanted to try a hearing aid when she was little—was told by her father that she couldn't because it would be expensive and pointless, anyway. Trying to chart a middle course, they let Jehanne decide for herself whether she wanted to try a hearing aid; she did, one summer when attending camp

at Gallaudet. It was hot pink. She wore it about a week. . . .

"Do you think this baby's hearing?" Candy asks Sharon afterward, when they are having lunch in downtown Frederick.

"I don't know," says Sharon. "I can say that I hope the baby's deaf, but to say I feel it's deaf, no."

They are talking about an old saying in the deaf community: If the mother walks into a place with loud music, and the baby moves, the baby is hearing. "If you base it on that, I do think it's deaf," says Sharon.

"I just say to myself that the baby's deaf," Candy says. "I talk as if the baby's deaf. If the baby's hearing, I'll be shocked."

"You better be prepared" Sharon tells her. "With Jehanne, I prepared myself. It could happen." Thinking about it, she speculates: "A hearing child would force us to get out and find out what's out there for hearing children. Maybe that would be nice."

Candy looks at her, amazed.

"It's not that it's my preference," says Sharon. "But I'm trying to think of something positive." . . .

In trying to know how to think about Sharon and Candy's endeavor, there are any number of opinions a person might have. Any number of abstract ideas a person might work through in, say, an ethics course. Are the women being selfish? Are they inflicting too much hardship on the child? How does one think of them compared with, say, a mother who has multiple embryos implanted in the course of fertility treatments, knowing that this raises the likelihood of multiple births and, with it, birth defects in some or all of the babies? Morally, how much difficulty can a parent impose on a child in order to satisfy the desire to have a child, or to have a certain kind of child?

A person can think about this, and think about it, but eventually will run up against the living, breathing fact of the child herself. How much difficulty have Sharon and Candy imposed on Jehanne? They haven't deafened her. They've given life to her. They've enabled her to exist. If they had used a hearing donor, they would have had a different

child. That child would exist, but this one wouldn't. Jehanne can only exist as what she is: Jehanne, bright, funny, loving, loved, deaf.

And now what about Gauvin, who, at three months, already resembles his sister? He has the same elfin face shape, the same deep dimples when he smiles. On his head is a light fuzz of hair; bulkier now, alert and cheery, he's wearing gray overalls and groovy red leather sneakers. The question that will be answered this February afternoon, at Children's National Medical Center, is whether Gauvin, like Jehanne, is deaf. Whether the coin has landed on the same side twice. By now, Gauvin has had an initial hearing screening, which he failed. They considered this good news, but not conclusive. From there he was referred to this one, which is more sophisticated. The preliminaries take awhile. Sharon lays Gauvin in a crib and a technician applies conductive paste at points around his head, then attaches electrodes to the paste. He needs to be asleep for the test, in which microphones will be placed in his ears and a clicking noise sent through the wires. Through the electrodes, a machine will monitor the brain response. If the waves are flat, there is no hearing. He stirs and cries, so Sharon breast-feeds him, wires dangling from his head, until he falls asleep. The technician slips the microphone in his ear, turns on the clicking noise—up and up, louder and louder—and the two women look at the computer screen. Even at 95 decibels, a sound so loud that for hearing people it's literally painful, the line for the left ear is flat. But there is a marked difference in the right. For softer sounds the line is flat, but at 75 decibels there is a distinct wave. The technician goes to fetch the doctor, and the mothers contemplate their sleeping son, who, it appears, might be neither deaf nor hearing but somewhere in between.

The doctor, Ira Weiss, bustles in; he is a white-haired, stocky man, jovial and accustomed to all sorts of parents, hearing and deaf, happy and sobbing.

The technician points to the wave and suggests that perhaps it represents some noise that Gauvin himself was making. "No," says the doctor, "I think it's not just noise." Sharon looks up at Candy and lets out a little breath. The doctor disappears to get

a printout of the results, then returns, reading it. Gauvin, he says, "has a profound hearing loss in his left ear and at least a severe hearing loss in his right ear.

"It does appear," he adds, "that his right ear has some residual hearing. There might be some usable hearing at this time. Given the mother's history, it will probably get worse over time. If you want to take advantage of it, you should take advantage of it now. Right now it's an ear that could be aided, to give him a head start on spoken English. Obviously, he's going to be a fluent signer."

At this stage, Weiss says later, a hearing parent would probably try a hearing aid, in the hope that with it, that right ear could hear something. Anything. A word, here and there. A loud vowel. Maybe just enough residual sound to help him lip-read. Maybe just enough to tell him when to turn his head to watch someone's lips. Hearing parents would do anything—anything—to nudge a child into the hearing world. Anything—anything—to

make that child like them. For a similar reason, Sharon and Candy make the opposite choice. If he wants a hearing aid later, they'll let him have a hearing aid later. They won't put one on him now. After all, they point out, Sharon's hearing loss as a child occurred at below 40 decibels, which meant that under certain conditions she could make out voices, unaided. Gauvin's, already, is far more severe than hers. Bundling Gauvin up against the cold, they make their way down the corridor, and into the car, and home, where they will tell Jehanne, and Jan, and friends, and family, a sizable group, really, that wants to know. He is not as profoundly deaf as Jehanne, but he is quite deaf. Deaf enough.

### DISCUSSION QUESTIONS

1. What reactions do you have to Sharon and Candy's wish for a deaf child?
2. Would you have wanted them to wish for a child who was not hearing impaired?





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