

BOOK CLUB

A NOTE FROM THE AUTHOR

Dear Reader,

True Biz had its earliest origin in a news clipping I read about a cochlear implant company facing legal repercussions for implanting malfunctioning devices in deaf patients. Even after they had evidence that a large number of the devices were faulty, they'd continued to sell them. The idea that a company had approved defective apparatuses for surgical implantation into people's heads, knowingly and for years, struck me deeply. I spent a lot of time thinking about why the scandal hadn't been a bigger news story. I spent even more time wondering what that experience might feel like for the deaf person.

At the time, I was out in Cincinnati feeling a little bit like an alien. In the U.S., I'd lived only on the East Coast, and I was accustomed to a faster pace and a certain brashness that some mistook for rudeness but in which I found a familiar comfort. In Ohio things were slower, and people were allegedly nicer. But I found them more wary of my Deafness than in New York or Philly, where people aren't surprised by much of anything, let alone me.

So I spent a lot of those early days in Ohio wandering around alone, photographing abandoned buildings, writing, drinking too much coffee, and generally sticking out like a sore thumb. Then one night I walked by St. Rita School for the Deaf and saw a few girls, middle school-aged, who had come down from the dorms, giggling and brimming with secrets. I waved to them and stopped to talk. Our conversation unfurled the way Deaf conversations often do—as if we'd known each other for much longer. One day, they said, they too wanted to make it to New York City. Normally, talking about things back home made me wistful, but that night I realized a piece of home was in the arc of those girls' hands, encoded into the language itself.

Society creates a lot of barriers for deaf and hard-of-hearing people, challenges that we take on daily with little recognition from the hearing world, and these are no doubt at the core of this book. But there is also an immense joy in Deafness, in sign language, and being in community with other Deaf people. I hope you find some Deaf joy here, too. Thanks so much for reading.

SARA

OP-ED: DON'T FEAR A DEAFER PLANET

This piece by author Sara Nović was originally published in The New York Times on October 10, 2021.

In Deaf culture, we have a rich storytelling tradition, including a stable of myths passed down through generations of deaf people. One of these stories is about a planet called Eyeth, a utopic world where deaf people communicate freely and live without stigma. Rather than the audio-centric societies that dominate Earth, Eyeth centers the eye. In some tellings everyone on the planet is deaf; in others, the society is designed around visual communication and signed language, and everyone signs regardless of hearing status.

Back here on Earth, most deaf and hard-of-hearing people know how very far away the dream of an unstigmatized existence really is. In the United States, deaf people experience inequitable access to the justice, health care, and education systems; increased incidences of employment discrimination, and police violence; and higher levels of sexual-based violence than their hearing peers.

While some of the discrimination we face comes from a place of ill intent, I'm willing to wager that most of it comes from ignorance and inexperience. According to the 2011 American Community Survey, about 3.6 percent of the United States population is deaf or experiencing severe hearing loss, meaning many average-hearing people have never had a meaningful relationship with a deaf person. Worldwide, the World Health Organization estimates that more than **5 percent of the global population** has "disabling" hearing loss, still a relatively small number. Without that personal connection, deafness remains amorphous, inscrutable, even scary.

But what if the population of deaf and hard-of-hearing people were to grow?

In March 2021, the World Health Organization released a report predicting that unless measures like increased access to health care and noise protection are enacted, 2.5 billion people worldwide, or one in four people on Earth, will have some degree of hearing loss by 2050. Nearly 700 million of them will experience hearing loss ranging from moderate to profound, a 63 percent increase from today's numbers. An uptick in global noise pollution and unsafe listening practices, childhood disease resurgences because of vaccine hesitancy or limited international availability, the use of ototoxic antibiotics and a lack of preventive ear and hearing care and hearing care specialists worldwide are some of the main causes of hearing loss cited in the WHO's report.

Reports of hearing loss linked to Covid-19 infection have also been documented, though the data sets are small. Still, one thing is clear: The future of humanity is about to get a lot deafer.

No doubt many people learning this news will want to know how to "fix" it—with a technological or scientific advance, or "cure," that will stop the coming of this deafer world. And while assistive technologies like hearing aids and cochlear implants are powerful, often transformative forces in the lives of deaf and hard-of-hearing people, they may not be the most effective way to reckon with widespread hearing loss of varying degrees. Rather than a purely curative focus, we should be attempting to eradicate the stigma that surrounds hearing loss.

A society-wide attitudinal shift like this is certainly ambitious. But we have a sort of blueprint for a successful deaf-hearing integrated society, an Eyeth right here on Earth: a community built in the 18th and 19th centuries on Martha's Vineyard.

In the late 1600s, a deaf carpenter named Jonathan Lambert and his wife, Elizabeth, landed on Martha's Vineyard as part of a subset of colonists from Massachusetts Bay. Many of them shared ancestry tracing back to Kent, England, and this, combined with the difficulty of the journey from the island to mainland, meant very little genetic diversity was introduced there for nearly a century. The result was a high incidence of hereditary deafness: while roughly 1 in 5,700 Americans at the time was deaf, on the Vineyard it was 1 in 155. A sign language developed on the island. It was known as Chilmark Sign (named after a town on the island), and later called Martha's Vineyard Sign Language (MVSL). It was used by both deaf and hearing islanders, allowing for fully integrated work, worship, and social interactions. Hearing people sometimes signed without deaf people around, and some islanders reported not being able to remember who was deaf or who was hearing.

The deaf population on Martha's Vineyard peaked in the 1850s, but increased travel ability made it easier for people to come and go, introducing genetic diversity to the island population. Meanwhile, on the mainland, the American School for the Deaf in Hartford, Connecticut, founded in 1817, drew increasing numbers of deaf students, teachers, and community members into its orbit. MVSL was either absorbed or overtaken by the American Sign Language (ASL) forming at the deaf school, and by 1952, MVSL was considered extinct.

The lesson from Martha's Vineyard is simple: When society doesn't make deafness a barrier, it isn't one. And all this was done with a 0.65 percent deaf population—imagine the profound changes that an integration of a deaf or hard-of-hearing population as large as 25 percent might make.

Today's world isn't ready for a deaf future, but it can be. Rather than an approach that's reactive and narrow—like CRISPR-editing hereditary deaf people out of the genome, or heaping on retroactive accommodations designed to maintain the status quo—we can take a proactive, cultural approach that incorporates universal design, dismantles structural barriers, and includes deaf people from the ground up.

As on Martha's Vineyard, an inclusive future requires community cooperation. Ideally, this would mean hearing people learning the signed language of their local deaf community (ASL in North America). Unfortunately, the hearing world tends to resist learning to sign.

Part of this is because of misinformation that learning to sign will delay speech, and in other cases, it's the result of a dearth of resources, particularly for working families or in rural areas. Making ASL classes and materials widely available, and integrating ASL into the public education curriculums and early childhood settings would support deaf and hard-of-hearing people and their families.

But if teaching the world to sign isn't feasible, we can still learn from the Vineyard signers by applying their overall mind-set recognizing

deaf and hard-of-hearing people as equal citizens who deserve to live alongside hearing ones.

Consider, for example, subtitles. Closed captioning is an inexpensive and widely available technology. Since listening and speech-reading is largely dependent on context and atmospheric conditions—for example, whether there is background noise—even those of the projected 2.5 billion people experiencing mild degrees of hearing loss are likely to benefit from captioned material. Still, content on many websites, video applications, and social media platforms remains uncaptioned. Even theaters often choose to forgo open captions, instead employing retrofitted "solutions" that overcomplicate and underperform.

At many movie theaters today, if closed captions are available at all, they are played in reverse across the back wall of the theater, written in little LED dots; deaf viewers are given pieces of plexiglass and must try to capture their reflection in order to access the film. While technically an accommodation that satisfies the requirements of the Americans with Disabilities Act, it doesn't work well, and the device causes the user to literally stick out in a crowd, reinforcing the stigma of deaf people as strange or different.

If captions were simply played on the big screen, everyone could enjoy the film together. But, because many hearing people dislike the aesthetic, and have likely never considered that deaf people live in their community and enjoy watching movies, society chooses to prioritize the unadulterated pleasure of certain viewers over accessibility for all.

A movie theater is a single, low-stakes example of the many barriers a deaf person faces every day, but it's indicative of the way a slight tweak of society's attitude could have a huge impact on the lives of many. Rather than make access all about hearing people's desire to avoid acknowledging their own discomfort with deafness, society could choose to reckon with the stigma it's built.

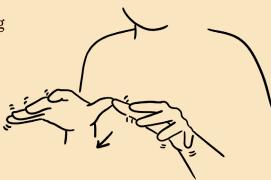
You needn't come all the way to Eyeth; simple interactions with deaf people here on Earth will reveal the truth of deafness as just another way of being human. As deafness is normalized, it will be easy to remember to save us seats at the tables at which you organize your events or draw up building plans for your theaters, so we can offer a fresh perspective on what works best, for all of us. One in four future readers may be grateful.

DISCUSSION QUESTIONS

- 1. How much knowledge did you have about the Deaf community and/or ASL before you started *True Biz*? In what ways did the novel reflect or augment your understanding?
- 2. Which character did you identify with most, and why?
- 3. The conversation around cochlear implants can get thorny quickly, which Nović illustrates throughout the novel with lines like "She's read about . . . parents deemed negligent for opting against surgery" and "Isolation was a requirement of the implant, her doctor cautioned." For Charlie, a defective device and poor instruction from doctors and parents leads to "oral failure" and a host of other issues. For other Deaf children, the procedure is so prohibitively expensive it isn't even a consideration. Discuss the pros and cons of cochlear implants, and the ethical considerations for parents, medical professionals, and device manufacturing companies, citing examples from the novel.
- 4. Nović shows so many varied examples of d/Deaf families and childhoods, from Charlie's ambivalent parents, to Austin's celebrated generations of Deaf folks, to Kayla's experiences code-switching from Black ASL to ASL, to the horrifying abuse Eliot suffers at his mother's church. Compare and contrast the experiences each student had growing up, and how those experiences helped mold them into the young adults they've become.
- **5.** Discuss Charlie's relationship with her mother. What, if anything, do they owe each other?
- 6. How does *True Biz* explore the ways the experiences of Deaf children, teens, adults, and elderly people differ?
- **7.** February is hearing but is headmistress of a Deaf school. Did you have any concerns about this? Why or why not?

DISCUSSION QUESTIONS

- **8.** What kind of responsibility did February have growing up as the child of Deaf parents? How are her childhood experiences similar to those of children of immigrants?
- **9.** Why does February confide in Wanda over Mel about the closing of River Valley? Do you think this was a betrayal? Why or why not?
- **10.** February's curriculum is interspersed throughout the novel. Describe the effect this had on your reading experience.
- 11. Like all teenagers, the young adult characters in the novel occupy one of life's in-between stages—as Austin notes when he's sifting through magazines at the doctor's office. "All of them were either adult in the worst way... or too childish." In what other ways do the characters—including the adults—straddle two or more different worlds? If each character were at the center of a different Venn diagram, how would you label the circles?
- 12. Slash may not be a great romantic partner for Charlie, but he proves to be a surprisingly great ally. What are some of the ways he shows this? How might you fight for accessibility for Deaf and hard-of-hearing folks in different areas of your life?
- 13. Charlie describes an attraction "not only to [Austin] but to the kind of person he was, the life that might have been hers if she had his stride and sureness and a hundred years of sign language coded right into her bones." Do you think it's common for crushes to walk this line between romantic attraction and envy?
- 14. In what ways did River Valley remind you of other schools in classic boarding school novels or movies? In what ways did it strike you as different?
- 15. Charlie is deeply affected by her experience of live music at the Gas Can. What are intense sensory experiences from your life?



RECIPES

Justice of the Pies Lemon-Lime Cake

Maya-Camille Broussard, founder and owner of pie company Justice of the Pies and author of the forthcoming cookbook *Justice of the Pies* (out September 20, 2022) is Black, legally deaf, and an extremely talented baker. Get a taste of what you can expect from her cookbook with this outstanding lemon-lime cake.

Supplies

- stand or hand mixer
- measuring cups
- zester
- Bundt cake pan
- knife

Ingredients

- 1¹/₂ cups unsalted butter, softened
- 3 cups granulated sugar
- 5 large eggs, room temperature
- 1 tsp. vanilla extract
- 1 tsp. lemon extract
- zest of one whole lime
- zest of one whole lemon
- 3 cups cake flour
- $1/_2$ tsp. kosher salt
- 1/4 cup sour cream
- 1 cup lemon-lime soda pop

Instructions

- 1. Preheat oven to 325°F.
- 2. Using a standing mixer or a hand mixer, cream butter and sugar together. Add 5 large eggs: Add and mix one egg at a time in order to create an emulsion. Add the zest of a lemon and a lime, vanilla extract and lemon extract, and mix.
- 3. Add cake flour in increments of 1/3, mixing the flour into the batter in between each increment. Once the cake flour is incorporated into the batter, add salt and sour cream and mix. While mixing the batter, slowly pour in the lemon-lime pop.
- 4. Line a Bundt cake pan with shortening and all-purpose unbleached flour. Pour the cake batter into the cake pan and bake for one hour in the center rack of the oven.
- 5. Test the center of the cake with a knife; if it comes out clean and dry then the cake is ready.
- 6. Remove the cake pan from the oven and allow it to cool for 10 minutes before removing the cake from the pan.

RECIPES

Skyline Chili

If you can't travel to Cincinnati for authentic Skyline Chili, make your own version at home with this duplicate recipe. Note: While Southern Ohioans love their Skyline, this recipe is not endorsed by the author. Try it and decide for yourself!

Ingredients

- 2 lb. ground beef
- 2 cups chopped onions
- 4 cups beef stock
- 28-oz. cans tomato sauce
- 2-3 tbsp. chili powder
- 2 tbsp. apple cider vinegar
- 2 tsp. Worcestershire sauce
- 1/2 ounce grated unsweetened chocolate or 2 3/4 tablespoons cocoa
- 2 tsp. minced garlic
- 1 tsp. ground cinnamon
- 1 tsp. ground cumin
- $1/_2$ tsp. salt
- 1/2 tsp. ground red pepper or 1/2 tsp. cayenne pepper
- 1/4 tsp. ground allspice
- 1/4 tsp. ground cloves
- 1 bay leaf or $\frac{1}{8}$ tsp. bay leaf powder

Toppings

- finely shredded cheddar cheese (certainly NOT optional)
- chopped onion (optional)
- kidney bean (optional)

For Serving

• Spaghetti or hot dogs and buns of your choice

Instructions

- 1. Brown ground beef and onion.
- 2. Drain.
- 3. Add beef stock to beef mixture and simmer 10 minutes.
- 4. Add remaining 13 ingredients, simmer uncovered 1 hour.
- 5. Remove bay leaf, skim off extra fat.
- 6. Serve over hot spaghetti, or hot dogs in buns for chili dogs.
- 7. Top with plenty of cheese and other toppings, like finely shredded cheddar cheese, diced onions, or kidney beans.

WANT TO LEARN ASL?

The best way to get signing is to learn from a Deaf teacher! Here are some recommendations for Deaf-led ASL instruction and resources.

Courses:

ASL Connect from Gallaudet University: virtual courses, including free intro course gallaudet.edu/asl-connect/asl-for-free

ASL at Home: a family curriculum aslathome.org

Deaf-Hearing Communication Centre: available online and in-person in the Philadelphia metro area dhcc.org/resources/aslclasses

Deaf Planet Soul: available online and in-person in the Chicago area deafplanetsoul.org/asl-online

Sign Language Center: available online and in-person in NYC signlanguagecenter.com/classes

Sign On: by the session classes signonconnect.com

ASL Video Dictionaries:

lifeprint.com

aslpro.cc

gcdasl.com

Apps:

 $The\,ASL\,App$

Marlee Signs (iOS only)

