

## Signs and wonder: There's more than one way to hear a story

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It was 1991 and the Royal Commission on New Reproductive Technologies was under way. The Women's Health Clinic in Winnipeg had funding for research to document women's experiences with prenatal testing, related technologies and birthing. Participants were to be people whose stories were rarely heard; for example, teenage mothers, recent immigrants whose first language was not English or French, and women with disabilities. I had one year to find 35 interviewees from varied backgrounds, develop the questions, conduct the taped interviews, synthesize the data and write the final report. It must have been Yvonne, a friend and equality and disability rights lawyer, who suggested I should hear from women who were Deaf, as part of the study. Thankfully, I could rely on the support of an efficient transcriber and an advisory group that included out-of-the-box thinkers like Yvonne.

Women who were hearing impaired certainly met our criteria for participants who were not commonly consulted about reproductive or other aspects of their health care. But I quickly realized that almost nothing in the previous four decades of my life had prepared me for this part of the job. I had never been friends with, or even interacted with, a person who was Deaf. I had seen the play *Children of a Lesser God*, a romantic story of a young Deaf woman demanding to be acknowledged in her own right. I had read about Helen Keller, who was both Deaf and blind, although many accounts focused on the heroism of Anne Sullivan, her teacher. I also recalled an intense conversation I had had years earlier with an anthropologist colleague, born hearing to parents born Deaf. As their only child, she had been

their interpreter to the outside world. Equally proficient in American Sign Language (ASL) and English, she had a profound understanding of the chasms between her world and theirs. "I suppose that is one of the reasons I became an anthropologist," she mused.

To connect with anyone in the Deaf community at that time, I needed a teletype (TTY) machine, an electronic device that used text, not voice, to communicate by telephone. The clinic purchased one, and I became its first user. I perused the manual, noting it was crucial to keep the list of abbreviations and protocols close by, especially *GA*, for "go ahead," to signal the other person should now respond; and *SKSK*, to officially end the call. Typing carefully, I contacted an outreach worker at the then Kiwanis Centre of the Deaf to ask whether some women in the Deaf community might be interested in participating. "Will check and get back to you. SKSK," she typed. There was excitement among the clinic's front-desk staff when a day or two later, the TTY alerted them to our first incoming call. "Three women interested," I read. "Now find ASL interpreters. SKSK."

I contacted the interpreter services agency, going back and forth by TTY to coordinate schedules. To my surprise, one of the women to be interviewed, Alice, requested two interpreters, one of whom had to be Deaf. In that interview, I was to ask my question, the ASL interpreter would sign to the Deaf "relay" interpreter, who would sign to Alice, and the sequence would be reversed when she responded. Feeling somewhat overwhelmed, I told Yvonne about the process.

She smiled. "Think about what she's willing to do to have her story heard."

As Alice explained to me during the interview, she had not had *any* language until age six and found it easiest to communicate with an interpreter who was also Deaf, rather than with someone who had learned ASL as a second language.

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Ringling the doorbell in the women's suburban homes triggered a light to let them know someone was at the door. As I entered, I was conscious of stepping across a threshold into a space where my everyday auditory cues had receded into the background, while I felt alert in new ways. The women were welcoming. Nina, the most outgoing, made it clear from the start that Deafness is not a disability but a culture. Touching her very pregnant belly, she said, "You may find it hard to understand, but I hope this baby will be Deaf. My brother is not Deaf; we love him, of course, but it is sometimes hard for him to be part of the family."

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I watched the women's faces, their signing gestures darting like starlings around the room, and heard their words through a voice somewhere off to my side. The women weren't primarily interested in discussing the pros and cons of genetic testing during pregnancy, but keen to offer recommendations for how prenatal and obstetric care might be more attuned to their particular needs. For example, they proposed that health care providers learn some basic signing, and that when ASL interpretation was needed for medical appointments, it should be paid for by provincial health plans. To improve the limited access to prenatal education, they suggested organizing support groups and specialized prenatal classes, provided by trained health educators from within the Deaf community.

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It was the women's descriptions of their birthing experiences that were the most palpable and riveting: Alice's frustration, as she hastily scribbled questions to the nurses between contractions while in labour with her first child; Nina's feelings of confusion about when to push, once administered an epidural; and Joan's fear when her twins were whisked away for testing immediately after birth, with no explanation. Joan leaned toward me, her signing emphatic and clear: "I just wanted to tell the nurse: 'Gesture, swallow your pride, don't leave me!'"

Through signs and wonder, I experienced a state of secular grace and would never be the same. I had learned there is more than one way to *hear* a story.

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These events took place more than 30 years ago. The names of the interviewees have been changed to protect their identity. Special thanks to Yvonne Peters, who gave consent for her name to appear.

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