

## Chapter Two

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# “So How Are You Planning to Communicate with Your Little Girl?”

AS ONE WOULD EXPECT, the first few months after Miranda’s diagnosis were eventful and difficult. I believe Elizabeth Kubler-Ross’s stages of grief are applicable to parents finding out they have a deaf (or disabled) child: denial, anger, bargaining, depression, and acceptance. I certainly experienced each of these stages.

With the diagnosis, it was not the imminent death of our child, but the immediate death of the dreams we had for that child that we had to grieve. No question, we had our tough times, but I believe Brenda and I moved through the stages pretty darn quickly.

I’m not sure why, but perhaps, for myself, it was the fact that I had a mentally disabled brother. Another thing that helped me adjust quickly was hearing awful stories about parents who did not accept their child’s deafness. I didn’t want to ever be accused of handicapping my child with my own hang-up about acceptance.

Though we mourned the loss of our “hearing daughter” and the dreams of a blond pixie with big brown eyes who would play duets on the piano with her mom and sing silly songs with her dad, we could now take some positive action. New visions began to bloom in our heads and new feelings blossomed in our hearts for our Miranda.

## Making Contact

The first conscious visual communication I had with Miranda happened within a few days of learning that she was deaf. In our kitchen, she stood up on a chair wearing only her diaper and plastic pants. With her curly blond hair, round face, and big brown eyes, all she needed was a pair of wings to become a cherub and take flight. I gestured for her to sit down and was quite surprised when she lowered herself. When she rose again, I motioned again for her to sit down. Again, she did. There was such satisfaction in this simple exchange.

In subsequent medical appointments, it was conveyed to us that with hearing aids and speech therapy, a deaf child could learn to speak and achieve a certain "normalcy." Brenda and I started doing a lot of research. We read whatever we could get our hands on about raising a deaf child. I remember reading a case history about how a little girl with a similar diagnosis should be able to develop normal speech and language skills and attend regular school. Once hearing aids were put on, she would instantly begin to develop verbal language. In six weeks, she would say her first word: "Mama."

I remember optimistically showing my in-laws the scenario. This case history raised expectations about this little girl of ours becoming "normal." I was cautiously optimistic. It took some time to get the hearing aids and earmolds for Miranda. It wasn't a pleasant experience for Brenda to take our daughter around to all the appointments with the specialists.

Brenda recalled that the hearing aid consultant, an older chap named Pete Keller, offered without being asked, "There's no Deaf community. It's just a bunch of deaf people standing around signing." In retrospect, we are horrified that a person with such a bias is one of the first "experts" that parents with newly diagnosed children would see. This negativity about the Deaf community was very much the prevailing attitude with medical and quasi-medical professionals we had contact with in Toronto in 1993.

When we received the hearing aids, it was not easy to put them in Miranda's ears and keep her pudgy, baby fingers from pulling them out. The high-pitched whistle of a misfit or recently removed hearing aid is

also not a fond memory. Once while visiting my Auntie Sue in Boston, we had to turn her house upside down looking for Miranda's hearing aids. My aunt is a seamstress who works out of her home, consequently there are stacks of clothing all around. Our two-and-a-half-year-old girl had taken her hearing aids out and stuck them under a pile of clothes, where they didn't whistle until someone moved the pile.

After several months of using hearing aids, it was very clear that Miranda Panda wasn't going to be like the child who suddenly became a "normal" kid after getting her hearing aids. This was somewhat disappointing. We were, of course, told that improvement would not occur overnight. Months went by, but we saw very little improvement in Miranda's ability to attend to sound. After a year, we decided the hearing aids were unnecessary. Miranda did learn to say, "Mama." But that was a few years later, long after she'd given up wearing hearing aids.

We did not wait until our daughter could "hear" or "speak" or had hearing aids to start communicating with her. Within days of the diagnosis, assuming that it was only natural for deaf people to sign, we started to learn American Sign Language (ASL). Our initiative was rewarded almost instantaneously. Miranda responded to our gestures and elementary signs by mimicking us. Soon, instead of whining, she was signing! And the more she did of the latter, the less she did of the former.

## **Hearing Assessment Program**

Three months after the initial diagnosis, the Hospital for Sick Children in Toronto had Miranda go through the Hearing Assessment Program (HAP). During a period of three consecutive days, the young child sees a team of specialists from each of the following departments: Otolaryngology, Audiology, Pediatrics, Auditory Training, Psychology, Speech, Ophthalmology, Social Work, CT Scan, Education, and Public Health.

After all the specialists have seen him or her, they come together at the end of the week to discuss the child's prognosis with the parents. Miranda certainly did not enjoy three days being tested, poked, and prodded by people in white coats. On the third day, she began getting upset anytime she saw a person in a white lab coat approaching.

The HAP didn't tell us much more that we had already known: Miranda had been profoundly deaf since birth; this was caused by an unknown reason, most likely, a recessive gene. Simply, her hearing did not develop "normally." It would be difficult, though not impossible, for her to learn to "listen" and "speak."

Perhaps the most interesting aspect of the meetings was the lack of a single deaf representative in the group of specialists, though there was a teacher who provided information concerning "the auditory-verbal approach to educating hearing impaired children." Fortunately, we did receive *The Parent Sharing Kit*, written and published by the Canadian Hearing Society, from the hospital's social worker. The kit contained a folder full of information about the resources available for parents of deaf children.

## Itinerant Teachers

Shortly after the diagnosis, we began to receive home visits from a teacher of the deaf provided by the Toronto Board of Education. The first teacher to visit us was named Joyce. She was a kind, supportive, hearing person who would come over once a week for an hour with a bag full of educational toys. She sat and played with Miranda. "Learning through play" was the approach. Miranda seemed to enjoy these visits.

I believe at this point we were confronted with the communication choice for Miranda's education: oral or Total Communication. We didn't know a lot yet, but we leaned towards Total Communication because it made the most sense: use all methods of communication available, including signing, voicing, lipreading, listening with aids, and so on. So during sessions with Miranda, Joyce would sign and voice mostly nouns. One of other goals of the visits was to teach Brenda and me how to interact with and teach Miranda.

As I was working during the majority of Joyce's visits, Brenda was the parent who received the training. One auditory therapy exercise had Miranda sitting with her back to the teacher who had a glass bottle. Then the teacher would drop toys or small items into the bottle, creating a sound to which the student is supposed to react. The idea behind

the exercise is to get the child to attend to the sound even if she can barely discern its occurrence.

“It’s not a bad exercise,” said Brenda. “But for us, it was a waste of time because Miranda was profoundly deaf. Of course we didn’t know that at the time. An audiogram with children that young is hard to get accurate. So it may be a good thing to do with other deaf children, but for us, it wasn’t much use. And Joyce wanted us to do it for a half-hour every day. For Miranda, it wasn’t interesting enough, and it is difficult enough keeping any two-year-old’s attention for even 5 minutes, let alone 30.”

After only a few months, because we indicated a preference for a Total Communication approach and Joyce didn’t have great signing skills, we started receiving visits from another teacher. Lee was a hearing woman who was married to a deaf man. Though we were at first excited to have a more fluent signer working with Miranda, ultimately Lee was a big disappointment. She was one of those professionals you run into who likes being “the expert” and telling the uneducated or uninformed what they’re doing wrong. This was a big problem for us because Lee tended to undermine our confidence, particularly with our nascent signing skills.

In addition to that, Lee didn’t know her boundaries and often tried to tell us how to parent (not only with our daughter but our son as well!). Ironically, and perhaps not surprisingly, this was an area she had no expertise in, since she was childless. Needless to say, Lee really rubbed us the wrong way. Her style was invasive and abrasive. Ultimately, we felt she did more harm than good for us.

When Miranda started going to the Happy Hands preschool at the Bob Rumball Centre for the Deaf (BRCD) in the summer, home visits with Lee were moved to after-school sessions at BRCD one afternoon a week. The relationship between Lee and Brenda did not improve there.

Brenda said of Lee, “She would do things like this: I’d have some plastic colored eggs, and I would sign to Miranda: BROWN EGG. Then Lee would jump in and say, ‘No, no. You can’t sign that. It’s a tan egg. You’ll confuse the child.’ Now, with my hearing son, I probably would have said, ‘brown,’ but she just had to jump in and show she was in charge.”

Things finally came to a head and Brenda told Lee off and put an end to the superfluous and counterproductive lessons. Unfortunately,

although we have had mostly good experiences with professionals regarding Miranda, we have had our share of negative ones. Typically, it is the insensitive remark like an audiologist asking Brenda, when Miranda was throwing a “terrible-two” fit, “Who’s in charge? The parent or the child?” Again, the audiologist was childless at the time and had no idea what a two-year-old is like on a full-time basis.

## Sign Language Classes at Home

Shortly after Miranda’s diagnosis, we contacted Silent Voice, a nonprofit service organization for the deaf and their families in the Toronto area. They provided early intervention services like in-home sign language classes free of charge for families of newly diagnosed deaf children. A few weeks later, on a Saturday, a young, attractive Deaf woman showed up at our home. Her name was Jessica. She was the first deaf person, other than our daughter, that I’d ever met. She communicated in four languages fluently: ASL, English (reading, voicing), Mexican Sign Language, and Spanish (reading, voicing). She began by teaching the whole family signs around the house.

The following week, she came with a friend, another young Deaf woman whose name escapes me now. This friend kept the children busy while Jessica taught signs to Brenda and me. This went on for a couple of months, and we really appreciated the introduction to sign language and the Deaf community on our own turf. Soon I enrolled into a sign language class at the BRCD, going every Thursday evening for a couple of hours.

## A Visit with a Deaf Family

Another helpful service that Silent Voice provided families like ours with was the opportunity to meet a deaf family, to give us more of an idea what successful deaf adults are like and how they live in the hearing world. Contrary to Pete Keller’s observation, Brenda and I were discovering that there *is* a Deaf culture, and that the deaf people in it are quite happy being who and how they were. To the members of the Deaf

community, deafness is not a disability. That idea was very intriguing to us.

Imagine having a disability but not feeling like you are disabled. It sounded like a great approach if one wanted to raise a child to be psychologically well balanced and self-confident. So we made the request to meet a deaf family.

Alfred and Shira and their two deaf sons arrived one Sunday afternoon for a visit with our little family. We were quite excited to have them come into our home. The kids played nicely as we got to know the couple, using our beginning sign language skills, their voicing and speechreading skills, and a good old-fashioned paper and pencil to communicate.

Alfred had a white-collar job working for the provincial government, and Shira, at the time, was a stay-at-home mom. They were warm and friendly. They drove a car and rented a house. It seemed they did just about everything our family did. It was an eye-opening experience. Being deaf certainly wasn't the horror show that I had imagined it to be.

## Communication Choices

“So how are you planning to communicate with your little girl?” This question began to come up frequently in conversations. I remember discussing this with Alfred after he asked. At the time, I didn't fully realize how important a question that was. We seemed to have three communication choices before us: oralism, Total Communication, or manualism. As I understood it, oralism proposed that deaf kids could learn to hear and talk without the need for learning sign language (or the Deaf community!). However, in order to succeed, it was stressed that Miranda would have to spend years going to speech therapists and other specialists.

As is my nature, I was skeptical after being told I could have a “normal” kid if I just did whatever the professionals told us to do. (As an employee of the Ontario Medical Association, I had a lot of contact with physicians and knew that they were mere mortals, not the all-knowing gods and goddesses of medicine many of them would like to be seen as.)

The Total Communication option seemed to make a lot of sense to me. This option called for the use of all the communication methods available: sign, speak, lipread, listen, gesture, mime, and, of course, write. In practice, this is what most deaf people do in the real world. As a mode for teaching deaf children, Total Communication in the classroom is often called Sim-Com (for Simultaneous Communication) where voicing English and signing are done at the same time. Because ASL is not English, an invented sign system called S.E.E. (Signing Exact English) is used.

I was quite disappointed when Alfred expressed to me his belief that Total Communication wasn't a good approach. I learned from him that most Deaf people considered S.E.E. a corruption of the beauty and efficiency of ASL. Alfred felt that manualism was the best option for people who were profoundly deaf from birth like himself and our Miranda. I began to hear that repeatedly from Deaf people, most of whom had been raised with the oralism or Total Communication approaches.

Manualism in a school setting is now supported by an educational philosophy called bi-bi, short for bilingual and bicultural. This philosophy has two basic tenets. The first idea is that ASL and English are different languages and should be treated and taught as such. The second idea is that deaf and hearing people inhabit different cultural spheres. At the time, I found this hard to understand and accept; but with repeated exposure, I have certainly found this to be true.

## Conference on Deaf Mental Health Issues

In May of 1995, I attended the fifteenth annual conference of the Ontario Council on Deaf Mental Health Issues held at the University of Toronto. I was part of a panel of parents who spoke about their experiences to mental health professionals who work with deaf patients. It was interesting for me to meet with other parents and hear their stories, particularly from parents with children older than my deaf preschooler.

I also had the pleasure to hear the keynote speech by Dr. Gerard Kysela, a professor in education psychology at the University of Alberta, who stated that a developmental view, rather than a disability view, would benefit a deaf child and his or her family the most. We had come to this conclusion as well.



Dr. Kysela's keynote presentation was entitled "How Families Cope with Deafness: A Family Adaptation Model." According to his research, families that have good coping skills and receive support acquire a new set of beliefs and values and adapt well to having a deaf (or disabled) child. He insisted that moving from the pathological (medical) view of deafness to an educational (developmental) view will lead families to concentrate on what the child can do rather than on what he or she can't do.

He said when professionals intervene, the intervention must be family-centered as opposed to the long-held practice of focusing on the child with the disability. Dr. Kysela recommended that parents "reframe the disability and contain the concept of disability to bring it into perspective."

Dr. Kysela advocated a bilingual (ASL and English) approach for language acquisition, as this method can best replicate the ten to twenty million utterances between a "normal" hearing child and a hearing parent, which researchers say is an average exchange over an eighteen- to twenty-month period. Also, he said the family's exposure to Deaf role models is important in their adjustment and the reframing of the disability.

I wrote an article about Dr. Kysela and the conference for the Ontario Medical Association's magazine, which appeared in the July 1995 issue. I am grateful to Jeff Henry, an assistant editor at the time and someone who befriended me when I started working at the OMA, for getting the article included in the issue that went out to all the physicians in the province of Ontario. The article's key message was that physicians, audiologists, and people who service the Deaf community need to view deafness from more than just a pathological viewpoint and to present all the options to families of newly diagnosed deaf or hard of hearing children.

## **Deaf Babysitters**

Two years before attending that conference, Brenda and I were already in the process of reframing the disability and adjusting our perspective. We were looking at what we could do to adjust to Miranda, rather trying to have her "change" for us. The key was getting to know more deaf people.

Some wise old soul, I'm not sure who, suggested that we hire a Deaf teenager to serve as our babysitter. This was one of the best things we did in the first few months after learning of Miranda's deafness. A deaf babysitter served three purposes for us: (1) we got a care giver who spoke our child's natural language fluently, (2) we got an idea of our child's potential from this deaf adolescent, and (3) Brenda got time to grow her piano-teaching business.

As it happened, Brenda had a friend from church named Paula Buckingham, who was a teacher's aide at the nearest high school, Danforth Technical Collegiate Institute, which had a Deaf students' program. Paula posted a help-wanted notice at the school as a favor to us and also encouraged a couple of girls to consider applying for the job. One of these teenage girls was named Hao Wen Kong.

Hao Wen remembers, "I called Brenda through the relay service. I can't remember what we talked about exactly. I do remember saying a few things about how I could teach Miranda and her parents sign language and Deaf culture. I had no experience with little children. I was a little mortified of making mistakes."

Hao Wen wanted the three-afternoons-a-week job, but because of her class schedule and extracurricular activities could only work two days a week. So she asked a classmate named Jodie to job share. We agreed to hire the girls under this arrangement. Brenda also agreed to pick them up after school and bring them over to our house to babysit for a few hours at a time so she could teach piano, run errands, and enjoy a few moments of freedom from the two kids.

One pleasant spring afternoon, when I arrived home from work, I was introduced to Hao Wen. She was an Asian girl with cute freckles decorating her cheeks, long dark hair, and an outgoing personality with a wonderful sense of humor. A few days later, I met Jodie, an African American girl, who was shy and sweet. Jodie smiled and nodded a lot. At first, we were only able to communicate with the girls writing in a notebook back and forth.

Hao Wen's enthusiasm was great. In time, when her schedule permitted, she became our permanent regular babysitter/nanny. As we got more proficient in signing, we learned more about her. She was a delightful person who was very popular in school, even with the hearing students. In fact, her boyfriend, Glendon, was hearing. They made a

sweet couple. According to Hao Wen, he learned to sign nearly fluently in a matter of weeks.

## Hao Wen's Story

When Hao Wen Kong was born in Guangzhou, China, in 1974, she had two hearing parents and two hearing brothers. Later, another hearing daughter named Helen was born. Hao Wen is very close to her younger sister. Because Helen is the only one who knows ASL, she serves the role of family interpreter. As Hao Wen recalled:

My deafness was caused by unknown reasons. My mother took me to several doctors. They said I would be able to hear if I took herbal medicines and had operations. The last doctor we saw told her that I would never hear again. My mother finally accepted that I am officially deaf.

We moved to Canada where my father and grandmother lived in 1980. Deaf education in Canada was valuable to me because the deaf schools in China were more expensive than the public schools [which my family could not afford].

In the fall of 1980, I was placed with an oral class at the Metro Toronto School for the Deaf. I had zero knowledge of letters, words, and numbers. It was frustrating to learn how to speak. Finally, in the fall of 1983, I was placed with a different class of children who knew sign language. I did not know more than twenty or thirty words because I was forced to learn to speak all the time without [learning] what the words mean during oral classes in the past.

I cried all the time because I was so frustrated and overwhelmed with advanced math, vocabulary, and grammar. I tried to communicate so hard with my classmates. It was a few weeks before they accepted me into their groups. Sign language unlocked my communicative barrier and pressures, and I learned so much from educational conversations.

Hao Wen went on to earn a bachelor of fine arts degree in illustration from the Rochester Institute of Technology in Rochester, New York. Now, she works as a CAD (computer-aided design) designer for the family business. She recently married her college sweetheart, Steven Glass,

who is a deaf man from Alabama. We stay in contact with Hao Wen via e-mail and still see her on occasion.

## **Hao Wen’s First Day Babysitting Miranda**

Hao Wen also recollected the first day of being our babysitter and what our daughter Miranda was like when she first met her:

When Brenda picked me up after school, I was kind of nervous. She knew almost no sign language. When we arrived at her house, we wrote to each other; however Brenda was anxious to learn and preferred to communicate with me through sign language. She was so eager to learn more from me about the different methods of sign language, ASL, PSE, and SEE, and Deaf culture.

I noticed that Miranda ran around and rarely looked up. Brenda told me she only made strange noises when she wanted something. I tried to chat with her but she wouldn’t look at me. So when she wanted a piece of cheese, I taught her the sign. I told her to sign ‘cheese’ before I gave her some. That was her first sign: ‘cheese.’

## **Inventing Instant Messaging**

Believe it or not, I invented instant messaging. It happened when I bought a second-hand Macintosh computer from my office to go along with the Classic II that I already had at home. I set the two computers up on the same desk. When I turned them on and opened the word processing applications the first few times Hao Wen came over to look after the children I’m sure she thought I was crazy. I communicated with Hao Wen by typing words on one computer screen while she typed on the other, taking turns to look over at each other’s screens. Why did I resort to this expensive, high-tech “solution?” I didn’t have a lot of confidence in my signing skills and was concerned that we wouldn’t be able to communicate effectively. Fortunately, I soon developed enough expressive and receptive skills that my two-Mac electronic instant messaging idea was mothballed. I wonder if all those in

the Deaf community using instant messaging realize they owe a small debt of gratitude to *moi*?!

For several years, depending on her schedule, Hao Wen babysat Miranda and Terence. We wanted Terence to know how to communicate with his sister, so it was important for him to be exposed to a deaf signer as well. Hao Wen was quite fond of him, describing Terence as “shy and sweet.” Terence liked Hao Wen as well and she became a part of our family. We enjoyed her company so much and we learned a great deal about deafness from our daily contact with her.

We were extraordinarily lucky to have Hao Wen come into our lives when she did, and our luck with finding great Deaf role models would continue after we enrolled Miranda into the Happy Hands preschool at the BRCD.