

Chapter 4

Meet the Daniels Family

Whenever I held my newborn baby in my arms, I used to think that what I said and did to him could have an influence not only on him but on all whom he met, not only for a day or a month or a year, but for all eternity—a very challenging and exciting thought for a mother.

—ROSE KENNEDY, 1890–1995

It is difficult, if not impossible, to understand the complexities faced by hearing parents of deaf children without first appreciating some of the challenges d/Deaf individuals have confronted throughout history as well as controversies over issues of communication and education that have created a decades-long divide. The previous three chapters serve as a preface to the story of the Daniels family and allow us to better appreciate their dilemmas and enter into their reality.

No life experience compares with the anticipation of the birth of a child in its ability to inspire hope for what will be. “I spend my down time hoping to feel the baby move. Every kick, punch, and swirl brings happiness to my heart. I love feeling the movement. I love this child so much already. I can’t wait to meet her. I can’t wait to hold her and kiss her fingers, cheeks, and toes. And, yes, I can’t wait to introduce her to this world.”

Such were some of the thoughts and feelings that played through Ginny’s mind as she carried her daughter in her womb, anticipating the birth and the changes it would bring to her life

and to that of her husband, Bob. Mingled with feelings of excitement and anticipation, however, intermittent and unvoiced “what if” questions surfaced from time to time. Considering the possibility of giving birth to a child with an exceptionality is most likely normal for most expectant mothers. For Ginny, who works as an activity therapy associate and nursing assistant with adults with developmental disabilities, such a possibility was one that could never be entirely dismissed, but it was not something that occupied a great deal of her attention.

Ginny and Bob grew up in the same neighborhood and attended the same schools. They became high school sweethearts and were married when Ginny was 23 and Bob, 25. After establishing themselves in their respective professions and purchasing a home, they began planning for the birth of a child. Ginny notes, “We were ready for a change in our lives and looked forward to the challenge of parenting.” Upon learning of her pregnancy, Ginny began journaling in a “pregnancy diary.” She documented normal neonatal development based on the results of a sonogram completed at 9½ weeks of gestation, adding, “Bob treats me like a queen.” At 14 weeks Ginny recorded hearing the baby’s heartbeat for the first time: “It was loud and strong.” Kyler was born in the wee hours of December 8, 1988, the product of an unremarkable full-term pregnancy, labor, and delivery. Kyler and her parents were discharged from the hospital at 10 p.m. the following evening after enjoying a steak dinner provided by the hospital and visits from family and friends.

Reflecting on her demeanor at the time Ginny observes, “I had always been quiet and shy, Bob was much more outgoing. I knew I would have to become more assertive in my role as a mother. I started to come out of my shell a little bit when we attended childbirth classes. I wanted to know as much as possible about what I was embarking upon. Little did I realize that childbirth would be a ‘breeze’ compared to the unexpected roadblocks we would come up against while raising Kyler.”

Their desire, as 30- and 32-year-old first-time parents, was to enjoy their daughter and delight in watching her grow, learn, and mature. Bob, a foreman with the city's property improvement program, went back to work almost immediately after Kyler and Ginny's homecoming. Ginny added two weeks to the standard six-week maternity leave at her place of employment in order to bond with her newborn and make sure caretakers were in place prior to her return to the workforce.

Ginny realistically reflects, "As I recall, life was good, but anytime you bring home a new baby there is stress . . . and [there are] questions. It was a totally different lifestyle." Among the stresses that had to be dealt with was the loss of Kyler's first two daycare providers in rapid succession after Ginny's return to work. Fortunately, Ginny was able to procure yet another daycare provider, one who was committed to caring for Kyler, following through on the feeding schedule Ginny provided, and providing the necessary stimulation for early childhood development.



Kyler at 18 months.

According to Ginny, Kyler was an “easy” baby—one who slept and ate well and appeared to respond to the stimuli in her environment. During her first year of life Kyler was healthy, with the exception of a few sniffles and one ear infection, nothing unusual. She loved books from a very early age and seemed to have an uncanny awareness of all that was in her environment. She was visually attentive to movements and sounds . . . or was she?

At 11 months of age Kyler’s childcare provider said, “I’m not so sure Kyler can hear.” Ginny recalls, “That got me thinking. I was upset and took Kyler to see a friend and told her I didn’t think Kyler could hear. We did some testing, banging pots behind her head, but there was no reaction. Her first birthday came shortly thereafter. When the party was over, Kyler was playing on the floor with balloons, and I popped one behind her head. She didn’t move at all. I started thinking, she doesn’t really respond to the dog. The dog barks like crazy. Nothing seemed to startle her.”

Ginny took Kyler for her 12-month, well-baby checkup. “I mentioned a possible hearing loss to Kyler’s pediatrician, and she said, ‘Well, I would have never thought that to be the case, but you’re around her more than I am, so let’s have her tested.’ Less than one month later, a local audiologist conducted an ABR [auditory brain-stem response] evaluation. He told us to keep her up all night long (which was very difficult) so that she would be tired in the morning for this test. They ended up sedating her anyway. I remember before we had the test done that morning, he clapped his hands behind her head, and Kyler turned her head. He said, ‘Oh, I think she can hear some.’ But we saw her hair move ever so slightly. The ABR test showed that the brain was not responding to sound.”

Kyler’s home state did not adopt legislation requiring universal newborn hearing screening until 1999, 11 years after her birth. Had universal neonatal screening been available at the time, the

screening of Kyler's deafness would have occurred within hours of her birth. Visually attentive children often mask the fact that they cannot hear by visually alerting to movement, which is often accompanied by sound, thus creating the false impression that hearing is intact.

At 14 months of age Kyler was reevaluated at a world-renowned hospital near the nation's capital for a second opinion. The otolaryngologist's report reads as follows: "Kyler was never bothered by noise in sleep. The parents never saw her startled by loud noise. She points when she wants something. She appeared to be a visually very alert child. At no time did she respond to environmental sounds while being observed in the consultation room. There was no evidence of verbal language comprehension. Only vowelized vocalization was heard."

The doctor notes that, in a soundproof booth, when presented with low frequencies at their loudest volume, Kyler responded by turning toward the sound, an observation followed by this remark, "Sounds presented at that intensity are known to create vibratory sensations." Based on no response to sound in the middle and higher frequencies, despite presenting sounds at the audiometer's maximum-volume output, the conclusion was reached that Kyler's "consistent and reproducible conditioned oriented responses [or lack thereof] were indicative of a profound bilateral sensory neural hearing loss."

Ginny muses, "I remember the car ride home was very quiet. Bob and I both had a lot of thoughts going through our mind. I had asked the doctor what could have caused this. 'Is there anything I could have done?' I had a healthy pregnancy, everything was normal; I took care of myself before I was pregnant. He assured me that it was not my fault, that sometimes it just happens or that it [the deafness] could be genetic."

Bob recalls, "When we went to the hospital for the evaluation, I knew she was deaf . . . but I didn't know how deaf she was. I cried

all the way home. I'm tearing up right now just thinking about it. It was good to get the results, but it was an emotional heartbreak. I'll be honest with you; I was pissed off that she was deaf . . . not at her, not at Ginny, but at everybody else . . . God and the whole bunch of them. Acceptance was my biggest problem . . . and the questions. Why? Why my daughter? I know these things happen, but why to us? It was a bad place to be, but we made it through."

Ginny concludes the story of that day: "We had an elderly dog, Jetta; she was my 'baby' . . . my first baby. She couldn't hear and was nearly blind. She had begun to attempt to bite Kyler. That same day [after arriving home from the hospital], I took Jetta and had her put to sleep. It was one of the most difficult decisions of my life. But I just thought I couldn't deal with it; I feared the dog was going to bite Kyler. Kyler couldn't hear me say, 'No, don't touch.' That was a day of pure agony." Bob adds, "I'd always said when the dog needed to be put to sleep, I'd take her up in the woods and do it myself . . . but I couldn't. I said, 'With the emotional heartbreak I've had today, I can't do it.' Ginny said, 'You watch Kyler, and I'll take the dog to the vet.' When we got home, she took her dog that she'd had for years and had her put down [to eliminate any possibility that Kyler would be bitten]."

One thing about living in a small community is that everyone seems to know everyone else or, at the very least, to know someone who knows the person with whom you are not yet acquainted. So it was that Kyler's pediatrician knew me and called to request that I meet with Ginny and Kyler. Ginny's follow-up call resulted in what was to become a twenty-two-year odyssey for the three of us.

My husband and I had moved to his rural home county from a metropolitan area. I had grave misgivings about the move because it required that I leave my position as a speech therapist at the state school for deaf children. Living in a more isolated area, I feared, would result in the loss of signing skills, professional

camaraderie, and the ability to access programs offering additional coursework in deaf education.

Shortly after our relocation, I was offered a position with my previous employer (the state school for deaf children) as a parent/infant educator. The arrangement would permit me to work in homes with families of recently identified deaf and hard of hearing preschool children in the westernmost region of our state. Such a position allowed me, for the majority of the week, to work within a sixty-mile radius of my home. One day a week I worked on campus, which gave me an opportunity to remain in close contact with my colleagues, maintain and continue to improve my signing skills, and keep benefiting from the school's aggressive staff-development agenda. After three years of itinerate teaching, I became pregnant. Following the delivery of our daughter I became a stay-at-home mom. Two years later our second daughter was born.

I continued my involvement with members of the Deaf community by interpreting worship services, as well as medical, social services, and legal appointments. This was prior to the days of the Americans with Disabilities Act. Such arrangements were both informal and gratuitous; thus I was able to arrive at a given location at a moment's notice with my daughters in tow to provide the needed interpreting service. I remember well arriving with a stack of books for my older daughter and manipulative toys for the younger one to keep them entertained while I signed and voiced the exchange between the deaf and hearing individuals.

I was named by gubernatorial appointment to the Board of Visitors, the governing board of the state school for deaf children. I had begun teaching sign language courses at a local community college and was also teaching courses and supervising graduate students who were completing practicum experiences through a graduate program at a liberal arts college.

At the time Ginny's pediatrician contacted me, my daughters were aged 5 and 7. Of importance at this juncture is the medical

condition of our younger daughter, as I have no doubt that it factored into the way I responded to Ginny and Kyler. Our daughter had been diagnosed with juvenile rheumatoid arthritis. On certain days her joints were so stiff and swollen that she was unable to walk. At 5 years of age, only months after my initial meeting with Ginny and Kyler, our daughter had major eye surgery to relieve pressure that had built up in her eye, a complication of her particular type of arthritis. The surgery with its required week-long, daily, anesthesia-free injections administered directly into the eye prevented her from losing the eye itself, although her vision would thereafter remain permanently blurred. Throughout her early years she was shuttled to monthly appointments with eye specialists, rheumatologists, and our local family practitioner.

My husband and I were faced with making treatment decisions often based on conflicting information. Treatment outcomes were frequently positive, but others had negative effects. Possible long-term consequences of her condition ranged from total remission to the fusing of all major joints and dependence on a wheelchair for mobility as well as possible loss of vision in what was now her “good eye.”

The obvious parallel with Ginny and Bob’s situation is the factor of the unknown. When it comes to the physical or medical conditions of one’s child, not knowing the impact the condition will have is the greatest source of concern—and fear. Fear, if not resolved or translated into action, can paralyze. It becomes the nightmarish “monster under the bed,” rendering parents incapable of moving forward.

Initial Interaction with Ginny and Kyler

It was against this personal backdrop that Ginny and I became acquainted. Our relationship from the beginning was uncomplicated, enhanced by what seemed to be a bond between mothers

of daughters, mothers dealing with unanticipated circumstances. We discovered that we shared the same birthday, as well as a yearning for spiritual well-being, acquaintance with a realm beyond ourselves, a realm that would lend a sense of purpose to our current realities. I daresay that Ginny confided in me no more than I confided in her. Our relationship evolved into one of mutual trust.

No longer employed as a teacher, I was released from my role as parent/infant educator, espouser of the current philosophy of how best to teach young deaf children. From the beginning of our relationship, Ginny and I seemed to be able to create a space where total honesty was practiced. I did not feel as if my training in the field of deaf education was null or that I no longer had an opinion about how to teach deaf children. I did feel, however, that all possibilities, all options must be explored (no stone left unturned) until Ginny arrived at a place where she felt confident about Kyler's potential for success. I was no longer entrenched in a philosophical paradigm that did not allow for reaching outside the box to consider other options. I was a professional, yes, but also a mother of daughters for whom I wished the best in all areas of their lives. I desired no less for Ginny and Kyler.

Without a full-time work schedule to impede my activities and with my daughters in school, I was able to spend significant amounts of time with Ginny and Kyler. My daughters were thrilled to have a young companion during their days at home, an audience of one who would laugh hysterically at their antics and give them her undivided attention. In time, Kyler imitated their actions, which were accompanied by perfectly mimicked facial expressions and mannerisms. Each animation was completed with the skill of a well-trained actress.

In addition to grabbing moments for "our girls" to be together, I visited Ginny and Kyler twice weekly for the following two years. During that time, I modeled signed communication

during noonday meals, bath time, while sorting laundry, playing outside and inside—taking advantage of the language-rich environment that is home.

Kyler was 13 months of age at our first meeting (1989). She was cherubic in looks. Her blond hair lay like spun gold in soft natural ringlets framing her porcelain-skinned face, delicately calling attention to her long-lashed, baby-blue eyes, which, chameleon-like, changed to azure, green, or Caribbean blue depending on the color of her clothing. Although shy by nature, upon arriving at a level of comfort, Kyler would act out all of her observations, imitating real-life characters as well as those she had seen in books and on television. She was innovative in choosing items from her environment that would allow her to “become” the character of the moment. Many times I expected Kyler to jump into the page of a book, joining the characters in their realm, much like Jane and Michael Banks had leapt into Bert’s sidewalk-chalk artistry accompanied by their nanny, Mary Poppins. Kyler’s imaginative play and interactive signed and gestured communication were accompanied by lips opening and closing in silent imitation of observed movements of articulators, movements that carried no sound to her deaf ears, the imitation of which did not disrupt the stillness or disturb her revelry.

While spending a great deal of time labeling all that was in Kyler’s environment, Ginny and I also made use of photographs, giving “sign names” to each family member and all those with whom Kyler came into regular contact. I encouraged Ginny to keep a written account of Kyler’s signed vocabulary, which she diligently maintained. The vocabulary log began on March 5, 1990, with a listing of 18 single signs. In May of that year Ginny noted that Kyler had begun vocalizing more and had signed her first sentence: “Eat cheese, please.” Ginny documents in the log, “She really seems to associate

saying ‘Mum, Mum’ with ‘Mommy.’ She says it a lot when she wants out of her crib.” At 28 months Kyler signed her first article spontaneously in the following sentence: “The dog eat.” In December of 1991 Ginny wrote the following notation: “Hundreds of words signed from 4/91–12/91 . . . can’t keep up.” Kyler had begun asking questions and responding to all manner of questions asked of her. A final entry recorded just prior to Kyler’s third birthday reads as follows, “The girl is in bed with the bear.”

A general rule of thumb is that at 1 year of age children tend to communicate in single-word utterances, at the age of 2, two-word utterances, and at the age of 3, three-word utterances. After that, utterances tend to expand in length and complexity, no longer corresponding to chronological age. As demonstrated by Kyler’s recorded sentence, she was communicating in multiple-sign sentences by the age of 3. The sentence quoted earlier consisted of eight signs, an amazing accomplishment for a child not exposed to accessible language stimulation until the age of 14 months.



Kyler at 2½ signing, “There duck fly.” She is pointing and signing DUCK at the same time, adding FLY in the second frame.



Kyle on horseback at 2½—love at first sight.

<table border="1"> <tr> <td>3</td> <td>5</td> <td>90</td> </tr> <tr> <td>15 mos.</td> <td></td> <td></td> </tr> </table>	3	5	90	15 mos.			<ol style="list-style-type: none"> 1. "Ut Oh" Signs "Ut-oh" everyday 2. bear 3. Sleep 4. eat 5. light 6. "No No" 7. Mommy / Daddy 8. Cheese 9. duck 10. Kitty 11. Eat drink 12. Shoes 13. Cup 14. Dog 15. bread 16. bed 17. Cow 18. flower 19. Sheep 20. cracker 21. Gate 	<p>As of 3-5-90 (Age 3y) 3 mos. Kyle has initiated</p> <p>(18) different signs copied</p> <p>(17) different signs understands</p> <p>(5) different commands</p> <p>3/14/90 Said "Ma"?</p> <p>claw shape to mouth? Not Mad n Drink?</p>
3	5	90						
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A page from the vocabulary diary Ginny kept of Kyle's sign acquisition.

Audiological Intervention

At 13 months Kyler was seen by an audiologist at a university speech and hearing clinic, a close personal friend of mine; a professional with multiple years of experience evaluating preschool-aged deaf and hard of hearing children and fitting them with amplification. Kyler's first audiology appointment followed auditory brain-stem response evaluations and initiated the process of fitting Kyler with hearing aids. Ginny summarizes the outcome of audiological intervention: "She was fitted with hearing aids; her diagnosis was profound deafness bilaterally. We tried behind-the-ear aids. We tried a body aid and an auditory trainer. We tried some kind of vibrotactile device, too. But she didn't respond to anything; it didn't really seem to matter." Ginny recalls the result of subsequent visits to the university clinic: "It just confirmed that Kyler wasn't getting any benefit from the hearing aids. Ann, you were there."

Indeed, I was there, and I remember well Kyler being fitted with binaural amplification and the expectation that she would begin making use of whatever residual hearing was available to her. Decreased hearing was thought to be exacerbated by frequent retention of middle-ear fluid and middle-ear infections; antibiotic treatment was recommended at the first sign of congestion. As Kyler became more familiar with the expectations regarding follow-up hearing evaluations the audiologist noted, "Her responses became more consistent and her response to sound more dramatic." When Kyler was 2 years old, a Phonic Ear FM system was introduced to maximize speech input by lessening the influence of ambient/background noise, thus reducing the signal-to-noise ratio and thereby providing a clearer speech signal.

Kyler's response to amplification in her everyday environment did not reflect the findings in the testing booth. I remember the

slow dawning that, despite the consistent use of hearing aids, Kyler was not orienting to sound, attending to speech production, or attempting to reproduce sounds or words. I accompanied Ginny and Kyler to their final audiological appointment at the university, joining Kyler in the soundproof booth. I wore a protective headset to prevent damage to my own hearing during the evaluation. I distracted Kyler with a ball of masking tape (sticky side out) while the audiologist introduced sounds into the booth. The purpose of the distraction was to minimize the possibility of a false response on Kyler's part. Various frequencies at ever-increasing volumes were presented; Kyler's eyes remained on the ball of tape as she rotated it inquisitively in her hands. It was only when the volume was sufficient to create vibrations that Kyler's gaze left the ball and searched for the cause.

The determination was made that Kyler was not receiving sufficient benefit from her hearing aids and that it might be wise to consider other options. By this time, Kyler was 2 years, 5 months of age, necessitating a quick decision if cochlear implant surgery was to be an option while Kyler was still young enough to obtain maximum benefit. The audiologist noted the following in his report: "Information regarding cochlear implant programs will be provided to Kyler's family." True to his word, he provided Kyler's parents with information about cochlear implants and hospital sites currently performing cochlear implant procedures.

Early Educational Endeavors

The most important period of life is not the age of university studies, but the first one, the period from birth to the age of six.

—MARIA MONTESSORI

Soon after my initial meeting with Ginny and Kyler, I contacted my former colleagues in the Family Education/ Early Intervention

Program at the state school for deaf children. In September 1990 they began providing weekly services to Kyler, who was at that time 14 months of age, and her family. Their goal was to make available to parents knowledge about deafness and to equip hearing parents with signing skills sufficient to provide consistent language stimulation and allow for reciprocal signed communication. This was accomplished by modeling language-rich interactions with Kyler.

Additionally, Kyler began receiving services through the county's Infants and Toddlers Program in March of 1990. These services included weekly speech and language stimulation provided by either a speech and language pathologist or the school system's teacher of deaf children. The case manager noted the following: "Loving, supportive, very secure environment. Strong family support network with numerous members of the family enrolled in a sign language course at the community college. The family is accepting of Kyler's disability, has contacted appropriate personnel for services, and is eager to learn about Kyler's needs."

Assessment data at 28 months indicated the following:

Cognitive skills are appropriate for her age. She adapts to form board reversals, identifies colors, knows the use of objects and understands size differences. Her language skills are at the 28 to 36 month level with some skills at a higher level. She signs in phrases, relates experiences from the past, knows several colors, knows prepositions and size differences and is beginning to express emotions through signs, but has not begun to imitate vocalizations. She imitates play activity, role plays and can participate in simple games. Kyler's self-help skills are at the 30 month level.

So it was that Kyler, during her preschool years, despite living in a rural area, benefited from an array of services that included parent/infant education, sign language interaction/modeling, speech and language therapy, and audiological intervention.

The only thing missing was the benefit from amplification. This would preclude the possibility of acquiring spoken language.

Philosophical Shifts in Deaf Education and Their Bearing on Kyler

Our state school for deaf children had in 1967 adopted what was called the “Total Communication” philosophy. Total Communication fueled the hope of finding middle ground in the age-old dispute between oralism and manualism, restoring a lost regard for sign language, and elevating reading levels for high school graduates (which at the time hovered at a third-grade equivalence). These anticipated results were cause for great excitement among parents, administrators, and teaching staff alike. While the first two goals were partially realized, reading levels for those graduating from schools espousing the new philosophy remained virtually unchanged, a result that was a devastating blow to those who had maintained high hopes that the glass ceiling for literacy achievements for deaf children would finally be shattered (see Johnson, Liddell, & Erting, 1989).

During my involvement with Kyler and her family, I taught a number of graduate courses (1983–1998), all of which were related to language and speech acquisition in d/Deaf and hard of hearing children. One of the texts selected for use by the Deaf Education Department of the college was Stephen Quigley and Peter Paul’s *Language and Deafness* (1984). The authors noted that exceptions to deaf adults’ poor reading abilities were found among those who enjoyed infant and early childhood learning experiences, early schema development, cognitive and linguistic development, making inferences, and engaging in figurative language and who also demonstrated the ability to use speech coding and recoding for processing text. In other words, findings were very positive for children who at an early age had

experience with learning models that supported the development of language acquisition, thinking skills, vocabulary development and a link between signed and spoken words that would later translate to better reading skills. Speech recoding was found to be important for hearing readers, not so much for access to word meaning as for temporary storage of words in the working memory, which allows for the comprehension of clauses and sentences. “This is one aspect of memory where deaf persons have been found consistently to have shorter spans than hearing persons” (ibid., p. 148). Although such abilities can be acquired in the absence of hearing, it is not typically the case.

Even though Kyler had the advantages of early childhood learning experiences, excellent cognitive abilities, and linguistic development, her ability to develop speech coding and recoding skills without the benefit of residual hearing was, for me, a huge concern. Although some successful deaf readers have no auditory input, they are the exceptions to the rule. Research at the time revealed generally poor reading levels among deaf high school graduates, which affected their academic skills across the board. Inferior reading levels among high school students persisted in large part due to weaknesses in English language competence as well as the inability to speech recode, a skill requiring temporal-sequential memory and one that is dramatically influenced by auditory input—or lack thereof. I expressed my concerns to Ginny as she considered how to respond to Kyler’s inability to benefit from more traditional types of auditory intervention.

Total Communication Didn’t Live Up to Expectations

Documentation of the failure of Total Communication to alleviate poor reading skills and weak academic achievement was extensive in the late 1980s and 1990s (Quigley & Paul, 1984; Johnson, Liddell, & Erting, 1989; Grosjean, 1992; Strong & Prinz,

1997; Erting, 1992; Johnson, 1994; Nover, Christensen, & Cheng, 1998; Svartholm, 1993, 1994).

As a result, beginning in 1990 with the Indiana School for the Deaf and continuing today, numerous programs and schools for deaf children began to embrace a bilingual-bicultural approach to teaching deaf children. The BiBi approach asserts that American Sign Language should be the first language of d/Deaf children in the United States and that English should be taught as a second language. The ultimate goal is proficiency in ASL and written English, as well as the attainment of social ease in both the Deaf and the hearing culture.

Ginny's choice to use sign language with Kyler was an easy one, in large part because of the additional delay that most likely would have occurred if an oral-only philosophy had been embraced, particularly in light of Kyler's lack of response to auditory stimuli. In addition, Kyler's rapid gains in vocabulary and connected language, as a result of exposure to sign language, was an exhilarating confirmation that using signs with Kyler was of great benefit. Although studies examining the Total Communication methodology had shown it to be less promising than hoped, there was as yet no track record on the use of a bilingual-bicultural approach with deaf children. BiBi remained in its infancy with no research on its efficacy. As a result, Ginny chose to use spoken English simultaneously supported with signs with Kyler.

Accessing Auditory Input: Is a Cochlear Implant the Answer?

Prior to Kyler's third birthday, she was evaluated at a medical center at Ginny's request to determine whether she would be a candidate for an implant. Criteria for children for whom a cochlear implant was being considered included a profound

sensorineural hearing loss in both ears, little or no benefit from hearing aids, no medical contraindications, high motivation with appropriate expectations (by child and parents), and placement in an educational program that emphasized the development of auditory skills after the implant had been activated. Kyler and her parents met the criteria, and the decision was made for her to receive an implant. “We didn’t just jump to [the decision to] have cochlear implant surgery right away. There was a year of making sure that Kyler wasn’t getting anything from her hearing aids.”

Upon Ginny’s request, the implant team provided her with a list of parents willing to speak with her about their decision to have their child receive a CI. Ginny first created a written list of questions and concerns and then contacted each of the families, posed her questions, and recorded their answers in a journal. It is clear that her deliberation to have Kyler undergo cochlear implant surgery was weighed with a heavy heart. She wrote the following: “Problem I am having is: How did you justify to yourself the risk you are placing on your child for a surgery which was not medically necessary? How did you explain what was going to happen to your child? Did you say ‘You are going to have an operation to help you hear?’”

At the time, Ginny and I talked at length about the pros and cons of the surgery. Although not wanting to influence the final decision, I must say that I was not unhappy when Ginny opted for the surgery. She recalls that it was a difficult decision for many reasons but especially because Bob did not wholly support surgical intervention. Ginny feared that, if the surgery were unsuccessful in any way, she would be to blame. Bob held the view that a cochlear implant was not a necessary surgery:

If she’d needed a transplant, or if surgery had been a matter of life and death, it would have been easy to allow them to operate. But this was a gray area . . . a matter of “quality of life.” Anything can go wrong when you go under the knife. To think of them messing around with her brain, cutting her

head open—was too much. She was my baby girl, she was born deaf, and I'd love her no matter what . . . whether she had a cochlear implant or not.

In the end Bob went along with Ginny's decision: "Ginny was much more affirmative about the CI. Ginny is very level headed; she's very intelligent. If I want the right answer, she has it; so I went with her on this decision. I trusted her judgment because she's never let me down in the past. I'm the one who makes bad decisions . . . surgery for Kyler was a decision I didn't want to make."

The doctors made it clear to Ginny and Bob that the surgery should not be considered a "quick fix." Ginny recalls the doctors explaining that "It will be a forever, never-ending process of learning how to use the implant and [continued follow-up] testing, and you have to be committed to it. I was warned that Kyler wasn't going to put it [the receiver] on and go with it. With any surgery there are risks." Ginny justifies the surgical procedure and numerous follow-up appointments this way:

After trying amplification with no benefit and knowing she was a bright child, I wanted to offer Kyler options to help her get through life and communicate the best. She's not from a family that's deaf; we are all hearing. I thought the cochlear implant would be the best option to help her communicate with both deaf and hearing individuals. I talked to other parents who had opted [for their children] to have the surgery, and I asked a lot of questions. It seemed like a cochlear implant was worth the chance. I watched some videos on children who had received cochlear implants. I understood the surgical procedure . . . the implant would be [permanently] in her head. If she didn't like it, or if she didn't want to use it later in life, she didn't have to wear it. She would be able to choose to use the cochlear implant or not when she was old enough to make that decision. The surgery was stressful because it was not a surgery that was a medical necessity. It was a choice, a life-changing choice."

Bob now agrees, "I look back at it now and say it was a godsend."

Ginny recalls the time constraint involved, “There was a time factor as well. If we were going to get it [cochlear implant surgery] done, we needed to get it rolling because the earlier, the better. I talked to somebody who mentioned an adolescent who’d had it [cochlear implant surgery] done, and he decided he just wasn’t wearing it . . . there was too much peer pressure. He’d grown up without it, and when you try to do something like that to an adolescent during the rebellious years, it is likely to fail.”

Thus, after a day of blood work and preliminary testing, Kyler received a cochlear implant on March 31, 1992. According to Ginny’s recollection, Kyler was the 41st child to receive an implant at this particular out-of-state university hospital. Implants were just beginning to be performed on adults with late onset deafness at an in-state hospital of greater renown. However, at that time the in-state hospital had not performed a single cochlear implant surgery on a child. As a result, Ginny opted to go with the medical team that had the most experience despite the fact that more than \$5,000 of the medical costs would have to be



Kyler following cochlear implant surgery.

paid out of pocket. This additional financial burden was due to the medical insurance provider's unwillingness to fully cover a procedure performed in an out-of-state facility.

Ginny was given a pamphlet developed by the company that created the Nucleus 22-Channel Cochlear Implant System (the system that Kyler would use). The pamphlet details the following differences between hearing aids and cochlear implants:

Hearing aids and other assistive listening devices simply amplify sound (i.e., make it louder). However, sounds provided by even the most powerful and effective hearing aids may not offer much useful benefit to those with profound bilateral hearing loss. A cochlear implant, on the other hand, is designed to provide useful sound information by directly stimulating the surviving auditory nerve fibers in the inner ear. (1989)

Approximately six weeks after the surgery, Kyler was to have the electrodes activated at a level that she could comfortably tolerate. Input would be regulated during successive visits until amplification provide a "sense of sound" at a volume similar to that of an individual with normal hearing.



Kyler insisted that her friends needed their ears bandaged as well (2½ weeks after surgery).

Opposing Views and an Independent Decision

State School for the Deaf Staff Opposed to the Implant

Ginny recalls an experience just one day prior to Kyler's surgery:

Some of the faculty members at the state school for the deaf were not very supportive of cochlear implants. We were leaving the following day to have Kyler's surgery when someone from the school faculty called me at work and said, "We really wish you would reconsider this surgery . . . that you would let her make her own decision when she's of age. You could possibly be making it more difficult for her to be part of the Deaf community and be accepted." I thought, "She's not part of the Deaf community; she's part of our community." The phone call just added more stress to an already difficult situation.

The state school for deaf children would not officially adopt a bilingual-bicultural model of education until August of 1993, one year and 10 months after Kyler's implant surgery. However, the waves of change had begun prior to the school board's vote to make it official, as is evidenced by the phone call Ginny received at work about her decision to pursue the surgical option for her daughter.

At the time of Kyler's implant surgery (1991) neuroscience had yet to establish the fact that when the auditory pathways are not stimulated early in life, the brain is less able to make use of aural information as time passes. The situation is comparable to that of individuals born with congenital cataracts that prevent them from obtaining visual experience in early childhood. As mentioned in chapter 3, they grow up to be functionally blind even after the cataracts are successfully removed (e.g., Sacks, 1993). A more thorough explanation of the impact of postponing cochlear implant surgery in terms of the brain's ability to make use of the new information it receives is given in a September 10, 2009, blog by a parent identified as

K. L., who posted the following on the ASL–Cochlear Implant website, <http://aslci.blogspot.com/> (accessed 09/24/09):

Many Deaf children's advocates recommend waiting to implant until the child is old enough to decide for him or herself if they want to get an implant. If all else was equal, I would be right there with them. The problem is that for the implant to be successful, the brain needs auditory input during the critical first three years. If hearing aids work for the child, great, waiting is good. However, for the profoundly deaf infant, hearing aids are rarely adequate in providing the needed auditory information across all the pitch ranges necessary to acquire verbal language. Therefore, waiting for the child to decide is the same as choosing not to implant at all. Because the chances are good that if you implant the 10 year old child who has had little to no previous auditory input, the implant won't work for them. It is not that the implant can't give them sound, it is that the child's brain is no longer able to adequately process that sound into meaningful information. So parents actually have no choice about letting their child decide. If they choose to wait and let their child decide, they ARE deciding. They are choosing not to implant. To implant or not to implant is, by default, a decision the parents WILL make, whether or not they even recognize that they are the ones doing the deciding. If you truly believe that this is a decision the child should make when they get older, how do you address the reality that by the time they get old enough to decide, they are too old to make good use of the sound the implant will give them?

Neuroscientists have accumulated compelling evidence to suggest that children with shorter durations of deafness prior to their implants fare better than children with long durations of deafness (e.g., Wilson & Dorman, 2008; Blamey et al., 1996; Summerfield & Marshall, 1995; Gantz et al., 1993). Speculation is that the result of sensory deprivation for long periods, which adversely affects connections between and among neurons in the central auditory system (Shepherd & Hardie, 2001), may allow

other sensory inputs to encroach on cortical areas normally devoted to auditory processing (i.e., cross-modal plasticity; see Balvelier & Neville, 2002). In other words, the brains of children become less “plastic” or adaptable to new inputs beyond their third or fourth birthdays, which explains why deaf children implanted before the age of 3 generally have better outcomes than those implanted later (e.g., Lee et al., 2001; Sharma et al., 2002; Dorman & Wilson, 2004).

Medical Staff Opposed to Continued Use of Sign Language following the Implant

Ginny recalls that “At the medical college [where Kyler’s surgery was performed], the audiologist and physician felt that continued use of sign language would hinder Kyler’s ability to process the sound she would be getting from the cochlear implant. They felt that she might not try to make the best use of the implant because she already had signs to rely on for communication.” This attitude among many in the medical community (and some audiologists) is not something that has only recently emerged as the result of the dawn of cochlear implants but rather is a myth that has been perpetuated since the earliest use of amplification. Despite evidence that the use of signs promotes early language acquisition, which is the foundation for the development of spoken language, for some implant teams, the legend continues.

The medical team would have much preferred that Ginny stop signing with Kyler. She explained:

I felt that would be devastating for Kyler . . . to just take away sign language. I prayed that sign language would enhance the use of her implant, not detract from it, and that it would help clarify the sounds she was hearing. If she could pair signs with sounds and words, she could make sense with the implant rather than signs being something that would distract her from the so called sound; (it’s not really sound; it’s electrical

stimulation). I can't even imagine how you would associate electrical impulses with words and understand if you didn't have something to connect it to. That was my thought. It was our hope that sign language would enhance the use of her cochlear implant, and it did indeed, as far as I'm concerned.

Being drawn into a philosophical debate during this anxious time of decision making introduced additional tension into Ginny's life. It created an unfortunate burden during a time that was already fraught with the weight of the importance of the decision at hand and with the pressure of being sure that it was the correct decision for Kyler.

Ginny asserted that "I guess they [the medical staff] thought the cochlear implant was powerful enough for kids just to depend on speech. I guess that's why they developed that technology . . . to make deaf kids function like hearing kids."

A Combined Approach Was Maintained

Ginny persevered in her conviction that sign language would augment Kyler's language and speech acquisition despite being cautioned by both sides of potential pitfalls resulting from a sign-supported speech protocol. If the implantation were successful, there would be no need for sign language. At least that was the theory espoused by the medical team. Concerns expressed by the professionals at the school for deaf children, on the other hand, dealt with their fear that Kyler would become disconnected from the Deaf community, a community that Ginny—and eventually Kyler—felt was not theirs. Regarding sign language and its benefit Kyler observes, "It really helped me connect words to their meaning; it was my main way of learning. Without signs, I don't know that I would have been able to keep up with my same-age peers in school or have been able to go on to college."

Kyler's Initial Response to the Cochlear Implant

The initial records from the medical center document Kyler's audiometric results before and after the implant along with scores from a battery of formal and informal vocabulary, language, and speech evaluations. They contain no mention of Kyler's initial response to sound either when the electrodes were first activated six weeks after the surgery or later, at the six-month follow-up appointment. The audiologist's report from her 12-month cochlear implant follow-up appointment also included no information on her response to the programming and mapping of the implant. Of the 22 channels in the implant, only 21 could be successfully implanted due to the size of Kyler's cochlea. After Kyler's CI was activated and programmed, the determination was made that two of the electrodes were considered to be "hot" and had to be turned off in a follow-up visit. The result was that Kyler has functioned with the use of 19 channels rather than the original 22. Ginny recalls no explanation of what was meant by "hot electrodes." Information about Kyler's two "hot electrodes" and having to terminate their use is absent from her medical and audiological reports.

My recollection of the time immediately after the activation of the electrodes is one of horror. I recall Kyler arriving home from the activation appointment with a broken blood vessel in her face as a result of screaming and crying during the mapping process. She was so sensitive to sound that moving a piece of paper startled her. Introduction to the world of sound was an unpleasant experience, to say the least. I called the clinic and, after describing Kyler's hypersensitive reaction to speech and environmental sounds, asked whether the intensity could be adjusted. Steps were taken to "remap" Kyler's implant, the result of which was a much better ability to tolerate auditory input. We have no way of knowing whether Kyler's hypersensitivity to the mapping process was a result of the "hot electrodes" and whether, as a consequence, the pain was sufficient to

cause her to scream with such intensity as to break a blood vessel in her face. Because Kyler could not adequately communicate the cause of her anguish, her parents, surgeon, and audiologist were in the dark as to what she felt or how to determine what trauma may have resulted from that particular incident. Ginny speculates that it is the memory of that episode that has plagued Kyler to the point that she becomes tearful each time the CI is remapped. Kyler's emotional response is one that continues to this day.

I remember feeling an overwhelming sense of responsibility and guilt with regard to the immediate results, concluding that never again could I support the decision for a deaf child to receive a cochlear implant. I recalled reading ancient tales of boric acid being poured into the ears of deaf children in an effort to "open" their ears and restore hearing. The practice produced horrific burns to and scars on their ears and face but did not, as one can imagine, enable them to hear. I pondered the possibility that cochlear implants might be the 21st century's parallel to such attempted cures of the past.

Thankfully, those thoughts and the accompanying guilt were a brief affliction. Kyler's extreme sensitivity to sound was temporary, and afterward she benefited mightily from the implant. Ginny concurs: "There was a period of time when we weren't so sure that Kyler was going to benefit from it [the cochlear implant]. She was uncomfortable with it at first. That was, I think, the only time I recall thinking, 'maybe this wasn't a good idea.' But that was short lived."

Acceptance

As a parent with no previous exposure to or knowledge of deaf individuals, Ginny ponders her ability to accept Kyler's deafness:

I've often wondered if my career as a teacher and caregiver for individuals with disabilities for the past 30 years helped

me accept this challenge. I feel that God chose me to be Kyler's mom because I could deal with her deafness. I've felt blessed to have been chosen to have this experience. My belief is that God is in control, no matter what happens, and He will get us through. He is the guiding Force. I'm sure my faith has made a difference [in my acceptance]. When a decision had to be made, we put it in God's hands, and everything seemed to work out. We prayed, asking for answers to the obstacles we were facing. You invited us to come to church, and that experience was something that really opened me up to my faith.

Ginny adds after a pause: "I won't say there weren't struggles in trying to figure things out. I don't want to sound like everything has been wonderful and that I didn't worry, that I gave everything to God and it worked out . . . or that this [life with a deaf child] has always been rosy—because it has not."

At my invitation Ginny and Kyler began attending a church where I had interpreted for deaf congregants for 10 or more years. Although Ginny was a member of another congregation, I extended an invitation because I thought exposure to an interpreted service could assist both mother and daughter in their sign language acquisition. They would also be in contact with d/Deaf adults with whom conversational sign language could flourish and also be among a community whose members had long been supportive of d/Deaf congregants. From that time until Kyler's graduation from high school, I served as the interpreter for worship services and Sunday school sessions and occasionally served as teacher for Kyler and her Sunday school peers.

Reflecting on the impact Kyler had on her life during those early years, Ginny muses: "Just having her, just the fact that I had a baby for one thing. As far as her deafness goes, I felt like every step of the way Kyler encouraged me. I can recall when she was about 5 or 6 years old; I said to her, just randomly,

‘How did you become so special?’ And she said, ‘God made me that way.’ ”

Kyler attributes her self-confidence and sense of self-worth mainly to her mother and her faith. Kyler reminisces: “She [Mom] was sure things would work out. I guess I got that positive attitude from her . . . faith probably had a lot to do with it. Before I would go to bed, she would say a prayer with me. I’ve seen prayer create miracles, and the power of prayer . . . that it really does work. Faith has made me a stronger person and [helped me] make better decisions in life. I always liked my Sunday school teachers. I liked going to Sunday school, of course. It was fun to go to school on the weekend to learn the Bible stories. They [the teachers] made a way to make it fun to learn about the Bible. And also I always liked to sign along to the songs. That was my favorite part!”

When asked about her sense of self-worth, Kyler responds, “He [God] decided to make me special, and He made sure that He gave me to parents that would accept me and not give me up for adoption like some parents would . . . or get rid of me. I think He created each one of us special, and He decided to make me deaf to bring a change on Mom’s life, a positive, necessary [change] . . . not negative.” Ginny laughingly concurs, “Drastic [change]!”

During her elementary school years, Kyler and her mother worked with the children’s choir at what had now become their church, teaching the children signs for choral musical selections. Kyler remembers that she became so interested in music that she and neighborhood friends wrote songs together. “I wrote one song called, ‘Are you ready for heaven?’ I thought it was inspiring to write little songs . . . I might be embarrassed about that now. I have songbooks we created. We recorded our songs on a voice recorder. I hope I burned that tape . . . a deaf person singing—I don’t think so.” Kyler giggles at the remembrance of it.

A Series of Miracles or Happy Coincidences

There seems to be a string of happy circumstances that have followed Kyler throughout her life. Ginny recalls, “Everything has fallen into place. Our pediatrician knew you. You knew the audiologist and teachers at the school for the deaf. Kyler’s pre-school teacher [at a local nursery school] just happened to be a certified teacher of the deaf. She wasn’t using her talents or skills at the time, and when Kyler came along she could do that. Also, you were a big connection when we needed an educator for the deaf [for the public school system].”

I contacted a teaching colleague from a nearby state who willingly joined the local public school system, initiating what became the first and only satellite program affiliated with the state school for deaf children. Deafness is a “low-incidence disability,” meaning that its occurrence will be infrequent among any age group in a given population. However, as noted in a local newspaper article in recognition of the five-year anniversary of the program, “There was an unusual cluster of children who were very close in age and had significant hearing loss or deafness. The program [was] developed because parents of deaf and hard-of-hearing children did not want to send their children away to school. The parents were concerned about being placed in a situation where their children would leave Sunday at 2 p.m. to go to the state school for the deaf and not return until Friday evening” (Martirano, 1997).

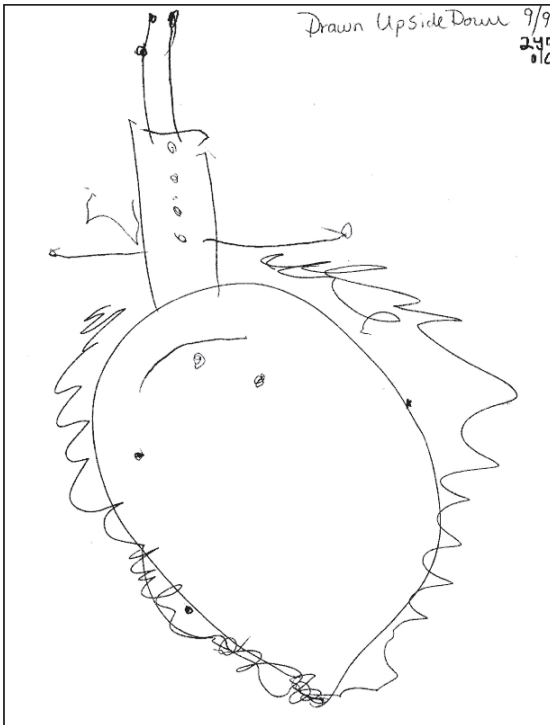
The article continued as follows: “A committee emerged that helped arrange the program’s administrative and academic goals, as well as the needs for its kindergarten and preschool students. An agreement between the county school system and the state school for the deaf in cooperation with parents whose children are involved in the program is completed every year. It includes an adjacent county which pays tuition [for its students]” (Martirano, 1997).

Funding for the satellite program's teaching position came from the governor's budget (a line item from the budget of the school for deaf children) with the local school budget funding employment of the two teaching assistants. The program served six children from prekindergarten through second grade, was the only one of its kind in the state, and was on occasion used as a model at national conferences on deafness. Kyler's parents were quoted in the article as saying, "The program is perfect for Kyler. There has never been a concept that this dedicated teaching team can't get across to Kyler." The team consisted of a certified educator of deaf children and two instructional assistants with signing skills. The affiliation among the schools continued until Kyler graduated from elementary school, after which time the state school for deaf children and the county remained on very good terms with the school providing consulting services on an as-needed basis throughout Kyler's graduation from high school.

One of the most important of those "happy coincidences" for Kyler, who has a penchant as well a great gift for art, is that she was the beneficiary of a cadre of excellent art teachers who supported and encouraged her talent throughout her public school education and into her college years. As a result, she has been the recipient of numerous art awards and has through the years had her work displayed locally, nationally, and internationally.

Kyler began drawing at a young age, an interest that both Bob and Ginny promoted. Bob, however, takes credit for Kyler's artistic gene pool. The drawing below was completed by Kyler at the age of 2 years and was drawn upside down. I found Kyler's drawing so fascinating that I purchased and read the text *Drawing on the Right Side of the Brain*. One of the primary techniques that the author, Betty Edwards, uses is to place an item or a picture upside down and have her students reproduce the model

from that orientation. She insists that the endeavor will result in a switch to reliance on the right side of the brain, unleashing creative abilities among those linear thinkers who find their artistic abilities subjugated by the left hemisphere of the brain. Elliot Eisner (2002), professor emeritus of art and education at the Stanford University School of Education, asserts, “The right hemisphere provides the location for much [*sic*] of the visualization processes; it is the seat of metaphoric and poetic thought, and it is where structure-seeking forms of intellectual activity have their home” (p. 99).



Kyler drew this figure when she was 2 years old.