

## Chapter Ten

# Parent Perspectives

“It wasn’t easy  
It was a long, hard  
Journey in life  
For us both...

But our love  
Held us together  
Through the traumas  
The ups and downs  
Of Life.”

—Marcia McDermott  
(Being A Mother, 2006)



# From Devastation to Expectation: Raising My DeafBlind Daughter

Barbara Caudill

When she was nine months of age, I learned that my daughter was deaf. It was in December right before Christmas. By the following December, I learned that she was also blind. Not a good way to celebrate the holidays. Of course, my husband and I had already suspected that something was wrong, but those were the times when the *official* diagnosis came from the audiologist and Wills Eye Hospital respectively. At that time, she only had a mild to moderate hearing loss.



My daughter at the age of 3.

When I first learned of her deafness, I was upset with the thought that my child would have a disability, yet I was hopeful because her hearing loss was only a mild to moderate loss. I hoped that hearing aids would help her. It was because her residual hearing could be enhanced with hearing aids that I decided to go the route of oral instruction with her. When I learned that she was also blind, I was devastated. I will never forget this strong reaction that I had in not wanting to go into her room to even look at her following the doctor's visit. I took her directly to my parents' home to regroup. My husband left me at the house with my parents. He did not return until the next day.

Initially, my daughter attended the school for the deaf. When she was in the second grade, it was quite apparent that her educational needs were not being met at that school.

## Early Education

My daughter left the school for the deaf and was accepted at Wilmington Friends School (WFS), a privately operated Quaker school. She was the only child in that school with such a profound disability. My reason for choosing WFS was because at the school for the deaf, I felt my daughter was not included as much as I would have liked. Much of this was because the other deaf children were so visual and it was just too difficult for them to include her in their communications. Even though



My daughter at the age of 6, attending class with her interpreter.

I realized that at the Friends School my daughter would be the only person who was deaf and blind, I still thought that some of the children would take an interest in her and that they might learn to sign, which is what happened there. By and large, it was a give-and-take situation, and neither place was utopia. Also, I believed that my daughter would get a far superior education at WFS and that would be so important for her future needs. Because she was required to repeat the second grade when she arrived at WFS, my daughter completed her secondary education at age twenty.

### **New Instruction**

All in all, I was extremely satisfied with the education she received at WFS. However; the only changes I would have made to her education are those countless times the educators gave her too many opportunities to complete her work in a timely manner. This ultimately was not helpful to her later on when she began college. Because many of the instructors felt sorry for her they lowered their standards instead of challenging her with higher expectations.

Except for that first year at WFS when my husband and I paid for her interpreter, the school system paid for all accommodations for my daughter throughout her education at WFS. In fact, that very first interpreter was my daughter's babysitter, and we were – and I am still – so very thankful that she agreed to do that for us. This young lady had just graduated from high school when my daughter began WFS. Thanks to this young lady, my daughter was able to learn so much immediately upon entering WFS.

### **New Access**

Her first piece of equipment was a Perkins Braille Writer; and a few years later, she received a Versabrilie unit. During middle school, my daughter was given a desktop computer and finally during her final two years in high school, she received a laptop computer, scanner, embosser, and TeleBraille. By far her favorite piece of technology was the Optacon. She would use the Optacon to read my mail and anything else that she could get her tiny little hands on. She always fascinated me by how thirsty she was for language and knowledge. Her petite fingers could decipher nearly anything. Braille, print generated by the Optacon, and even plastic toy letters were no match for her inquisitive mind.



My daughter at the age of 16 in her resource room at the Wilmington Friends School. The school emptied out an old supply closet to accommodate her specialized equipment.

During IEP meeting the team discussed my daughter's friendships. From the second through the sixth grades, my daughter had a wonderful social life. Then, in the seventh grade, those friends began to drift apart from her. Those were difficult times for her. Although the school was aware of the friendship issues, they did not present any special programs to help address it; they tried to encourage friendships through the Quaker traditions of service and caring. Unfortunately, their attempts were not very successful.

When she went away to college, I hoped that she would develop deeper friendships since she was attending a college for the deaf. However, this was not a good experience for her either. She did not feel included and began to isolate herself in her dorm room. The computer seemed to become her closest friend. Both my daughter and I decided that it would be best if she were to leave that school and try something closer to home. After a year at a local community college, she enrolled at the University of Delaware. Initially this seemed to be a better experience for her. Although, she did not have the *normal* experience of being on campus or being with her friends all of the time, she was able to attend some parties and even went out to dinner and dancing with some of the girls she met. One very negative experience for her occurred when she was asked to pledge a sorority and then was tersely turned down.

### **Reflections on the Journey**

As I look back on how well her transition from high school to college was, I recall how she had not wanted to attend college directly after high school. She had told me that she wanted to wait a few years. But I *encouraged* her to attend, and I should not have done that. In hindsight, I see that it would have been better for her to take some time off before going on to college. Other than that, it's difficult to say what else I would have changed about her transition process because I truly believe that we can only do our best to transition those with deafblindness, and each experience is different. My daughter's transition was not smooth, but it was much better than the stories I have heard from many other parents.

Comparing my daughter's early education experiences with her experiences at college, I can see that back in grade school when we were trying to have her fit in was when the worst problems occurred. This was during adolescence, which is an extremely difficult time for any child. All kids want to be liked and they worry about fitting in. Having any kind of difference can be difficult. To expect an adolescent to fully embrace a student with differences so that student can have the same experiences of non-disabled students is asking too much. This is a fact I have come to believe as I've been able to step away from

the daily pain and sense of rejection I saw etched on her face. After years have passed, I can assess things in a more realistic, pragmatic way. The elapse of time has aided and makes me less emotional regarding those situations when my daughter was left out of group activities and had her feelings hurt.

### **Looking Forward**

As I see things today, I feel that my daughter is capable of living independently; but I admit that I did not always feel that way. Before, I could not imagine her being on the streets alone with her cane and with little ability to communicate with those around her. But now I think that what has changed my mind is that I see how much she wants independence for herself, and her love and zest for life. Another sense of comfort is that she has recently been placed on the list for a guide dog. That additional support will be great for her. Also, there are so many new adaptive devices that can help her interact with those who do not have sign language skills to communicate with her. However, with all that said, I still worry about her and can't imagine her traveling on a subway negotiating a major city like New York by herself.

My hope is that one day my daughter will become gainfully employed and that she will have a happy, fulfilling life doing whatever makes her feel happy and fulfilled. My genuine desire for her is that she realizes the opportunity to be as independent as possible. Often I tease her and say that she can be independent in spite of me. The truth is, any lack of confidence I have is not in her so much, but in my *letting* her go to be independent. The Helen Keller National Center (HKNC) has been a great experience for her. She has received training there in the past, and recently she returned for updated technology training. I preferred not to be involved with the training aspect of life. For many years, I have been there to help, train, and love her. Now, I just want to be there to love her, support her, and be her friend.

Although at the beginning of the journey, there were many struggles to address her educational needs, I try not to focus on those negatives. Instead, I choose to focus on those who have been there throughout her journey, including teachers, interpreters, therapists, and people from state agencies and even the HKNC regional office. Without all of the knowledge, caring, and love shown throughout the years, the journey would have been very empty.

## **Leaving on Time: The Story of My Son's Journey to Post-School Success**

*Jill Fullerton*

As long as I can remember, I have been writing the story of my son's life. When he was born, I had such high expectations for the kind of life he would have. So far, my son's story has been plagued with more sadness than happiness. Graduating from high school has enabled me to reflect on all that he has been through. After recalling all that he has learned, I am hopeful that the remaining chapters of his life will be filled with more happiness than the beginning chapters.

Chad lost his vision between the ages of 4 and 5 due to optic neuropathy. He lost his hearing between the ages of 10 and 12 due to auditory neuropathy. Both losses were gradual. During that time, he also lost his fine-motor skills and much of his mobility as the neuropathy spread to other nerves in his body.

My initial reaction to hearing that Chad was legally blind was of course to cry for the loss of most of the dreams I had for him. I felt like all my balloons had just been popped. After finding out that he had also lost his hearing my mind was filled with questions and worry. *What more can this child possibly lose? How are we going to get him through school?* The questions, uncertainties, and feelings of hopelessness continued and still do today. No one has answers to explain why the nerves in my son's body are degenerating. Even though he has been seen by many doctors and put through so many painful tests, we still have no answers.

### **Reflections on Academic Pursuits**

After I learned that my son was legally blind, he continued in regular education classes because, as he got older, we realized his disabilities did not impact him cognitively. If information is presented to him in a way that he can learn, he is more than capable of doing anything academically as well, or in some cases, even better than many of his peers.

In grade school Chad used large-print books, received extra time to complete assignments, and was presented materials auditorally. As his vision loss increased, he began using a CCTV. When his hearing loss began to worsen, he used an FM system for a short period of time. When that was no longer helpful, he received a full-time 1:1 aide in the sixth grade to assist him with accessing information. In high school he continued to use the CCTV while the support aide typed information to him using a laptop computer attached to a CCTV or a large monitor. Both methods worked quite well for Chad since he is usually

able to understand much of the information he reads. In Math class, this method of using high-tech adaptive equipment was a bit more difficult so a large dry-erase board was used instead. This approach was particularly useful after he lost the ability to write with a pen or pencil. All the math problems, equations, and formulas were written on the dry-erase board so that he could more easily complete and see his computations. Whenever possible, teachers would give him typed class notes ahead of time which made it a lot easier for him to follow the class lectures.

Because of the slowness of these approaches (the use of a large dry-erase board and laptop computer hooked up to a CCTV), it was decided that it would be best for Chad if his remaining Math courses (Algebra II, Geometry, and Trigonometry) were taught by an instructor working with him individually.

Throughout Chad's school life, I've been extremely involved in all aspects of his education programs, especially since I realized his intellectual potential early on. However, getting the teachers and school administration to realize his potential was a difficult task. I kept in close contact with the school personnel who were intimately involved with my son; and I also started working part time for the school district. This enabled me to check in with his teachers to make sure everything was going ok; or to see if they had encountered any problems presenting material to him. Since Chad's ability to communicate with other students became an issue, some adjustments had to be made when projects were assigned that required him to pair up with his classmates or participate in group discussions. In high school my need to intervene became less as Chad took on more responsibility for obtaining what he needed. During this time, Chad's 1:1 support aides were extremely important to his success. As one can imagine, we had our share of good aides and bad ones. All these paraprofessional had tremendous impact on Chad's educational success as well as his frustration level.

Chad graduated high school at the age of 17, which is the age at which he would have completed school had he not been deafblind. As a family, we decided this was the best thing for Chad since he was fully aware of his academic success. He fulfilled all the required credits for graduation, and like other students in his class, was able to go on to college. We wanted him to realize that he had the cognitive ability to learn and do well in school if he received the information in an accessible format. By keeping Chad in high school longer, we felt he would have believed that, due to his disabilities, he was not capable of achieving academic success. By law, Chad would have been able to remain in school until age 21; however, had he remained in high school any longer, my husband and I really believed he

would have only doubted all of his academic accomplishments throughout the years. So, we decided that it would be best for him to go ahead and graduate on time.

After a lot of hard work and team support, I am now satisfied with the overall education my son received. It was not an easy place to get to, though. Many years of fighting with the school district were required in order to get him what he needed. By far, the greatest struggle was to obtain a 1:1 support aide who was qualified to assist him in his AP (Advance Placement) classes. One thing I wish I could have changed most was his "terrible tenth grade year" when he had a horrible paraprofessional/support aide working with him. Not only did this person not show up most of the time or refuse to take notes for Chad during class; but this aide also took a personal dislike to him. This personality conflict made Chad's life so miserable that my husband and I had to force him to attend school everyday. I believe that during that time Chad's health declined even further due to the added stress. In hindsight, I should have insisted more adamantly that this aide be removed from working with my son. Although I did try, the school district refused to listen to me or Chad. Even Chad's classmates complained to me about how poorly this aide treated my son, but they were afraid to approach the principal on his behalf. Chad ended up being out of school for three months on homebound schooling and did not receive an appropriate education during that time. My husband and I used our own resources to hire tutors to prevent him from falling behind or losing his academic status.

### **Reflections on the Process**

Looking back over the years, my son received a lot of extra support from my husband and myself, the Intermediate Unit and the school district in order to achieve the high level of success he has realized so far. So many sacrifices were made and opportunities presented to him that have had a tremendous impact on his life overall. Chad received vision, hearing (sign language instruction) and mobility support through the Intermediate Unit and the school district. The laptop he used was provided by the school district, the CCTV was provided by the Intermediate Unit, and the school supplied the monitor and paraprofessional who would type information to him. He also received one-on-one math instruction. In grade school we paid for three summers of tutoring and in high school my husband and I paid for whatever math tutoring he needed. We also paid for all the instruction he received during the time he was receiving homebound instruction in the tenth grade.

Friendships were one area where the school lacked any understanding of what challenges being in a regular education classroom represented for a disabled student. Two

of Chad's classmates learned fingerspelling from his sign language instructor. When he was in the eighth grade, sign language classes were offered to all students. However, most of the students did not participate in the classes and the few who did only wanted to learn signs that they could use to talk with one another, but not with Chad. The English teachers that taught my son in high school encouraged other students to type to him on his laptop if there was time, but that did not happen often. Three teachers in particular would take time themselves to type to Chad to get to know him on a more personal level. These teachers realized Chad's potential and encouraged, supported, and made the extra effort to give him every opportunity to excel in their classes. Truthfully, I feel that all of Chad's high school and middle school teachers realized his academic ability and offered him some level of encouragement and support. However, the commitment of these three high school instructors to ensure that Chad was afforded a positive education experience was really remarkable.

In high school I don't believe that Chad felt as though he were a part of his peer community. He spent so much of his time with adults (teachers and paraprofessionals) that he lost interest in his classmates. This was more because his classmates showed no interest in trying or wanting to communicate with him. He felt very isolated. In Chad's particular case, the lack of friendships was mainly due to the progressive deterioration of his hearing and mobility from the time he was in the fifth grade until the time he completed high school. Every few years we would have some new issue to deal with – not only related to medical and family concerns, but at school on a social and educational level as well. Basically, differences were a part of Chad's total school experience. As his disabilities progressed, we had to learn to be flexible and to teach the school district to be flexible as well. The biggest lesson we've learned through his transition process was to have a backup plan because things may not go as you want or expect them to.

### **Future Reflections on Independence**

While I do not feel that Chad is physically capable of living independently now, I do feel that he is intellectually capable. Before, I thought it would take several years before he was ready for independence; but I believe that after he receives independent living skills training for the deafblind, opportunities for career exploration, and exposure to social activities with other deafblind people, he will do just fine. He needs to be taught by people who are trained in deafblindness. Through this specialized training, Chad will learn that there are different ways of doing things than a sighted or hearing person would, but that things can be done nonetheless. Chad doesn't know or realize this fact yet as he has lived in

a sighted, hearing world all of his life and tried desperately to appear as normal as he could. I really do feel he can eventually be independent. He may need a bit of assistance with some things, but he has the capability inside himself. He just needs the confidence, specialized training, and advocacy to bring it about.

I want Chad to get specialized training so that he can go on to college. Ultimately, my desire is for him to find a career that suits him and has the accommodations he requires. I want my son to be able to live a happy, independent, successful life. Each step of the way, I have been right there for him. Although I am very apprehensive about the future, I am excited at the same time. Chad is starting down a different path in his life right now; and it is time for him to start writing his own story, so to speak.

## Small Steps toward Self-Determination: Learning How to Let Go with Love

*Victoria O'Neal*

When Cristen was about 4 or 6 months old, we discovered that she was not listening to us when we would call her name. One morning, I was in the kitchen and Cristen was playing on the floor with her back to me. I got two pan lids and hit them together, and she never moved. One doctor and then two doctors discovered she was indeed deaf. Gary and I



Cristen O'Neal as an infant.

were both in a state of disbelief. I had never smoked or drank and always watched what I ate. Of course, we went through the "Why me?" stage. One day I was talking to my mom about it, and she said something that I will never forget, "Honey, God gives those special children to people that he knows will take care of them." From that day on I was on a mission to get Cristen everything that she needed to live her life as normally as possible.

We had her fitted for her first hearing aid (at that time it was a body aid) and you can guess that the aid spent more time getting repaired than she had it because food and anything she drank went right into the microphone. Cristen also had a condition her pediatrician called eye nystagmus, where the eyes continually shift from left to right. He recommended that we see an eye specialist when she was about 18 months old. The ophthalmologist discovered that Cristen also had a low vision problem and should be fitted for glasses. From day one, Cristen never was bothered by wearing her glasses or her hearing aids. She was always very responsible to take care of them, even at an early age.



Cristen O'Neal at age 3.

Cristen's audiologist recommended that we enroll her in the Easter Seals program so that we could start learning sign language. The thought, at first, scared me to death. I said to myself, "This is like learning a whole new language," and I did not know at first if I could do it. That thought soon passed, and I was suddenly buying every book and dictionary on signing that I could find. I took Cristen to the nearby town of Franklin twice a week for the Easter Seals program. Reading to my 2-year-old daughter was quite a task; for every word, I would need to stop, look up the sign, and show it to Cristen. I am sure that she never really got the meaning of the story at first because of this. Soon I decided that, instead of

signing every word, we would look at the pictures in the book. I would give Cristen the signs for the things in the pictures, and then tell her the story based on what was happening in the pictures. She then would continually bring me things around the house, and I would look up the signs for them and show her.

When Cristen was about 3 years old, we started her in a preschool program at Clarion University. Undergraduate students in Speech Therapy, under the direction of Dr. Colleen McAleer, would work with Cristen twice a week. She started to utter some recognizable words, "NO" being the first word soon followed by "Mom" and "DaDa." That was about the extent and still today is the extent of her speech ability.



Cristen O'Neal at age 5.

At age 4, Cristen was enrolled at North Clarion Elementary through the Intermediate Unit VI (IU-6). The following year she went to West Forest Elementary in her second



Cristen O'Neal at age 2.

hearing impaired class through the IU. Then the following year, she started first grade in a hearing impaired self-contained classroom at Steffee Elementary in the Cranberry School District. She continued at Cranberry through her high school years and was mainstreamed into some classes such as gym, typing, and computer keyboarding. For a majority of the time, she was in the hearing impaired classroom with four other girls who were her age.

When Cristen was in about the tenth grade, the state vocational rehabilitation agency for the blind requested that the regional representative from the Helen Keller



Cristen O'Neal at age 12.

National Center (HKNC) contact us to discuss transition services. The regional representative came to our home and discussed our daughter's education. My husband and I learned about the HKNC training program located in Long Island, New York, and we were terrified at the thought of sending our only child to such a far away place. I recall how I initially thought to myself, "No way will I ever send my child to New York!!" The regional representative also shared information with us about a one-week transition

program in Richmond, Virginia. My husband and I decided to try that program first. Cristen

enjoyed herself, and I think that began her feeling of independence. The following summer, the HKNC regional representative encouraged us to allow Cristen to participate in the two-week summer program at HKNC. We decided, reluctantly, to send her. She missed us a lot, but said that she did have fun.

When it was time for Cristen to graduate from Cranberry, the HKNC regional representative attended her last IEP meeting and suggested that we consider having our daughter stay in school for her remaining two years of entitlement so that she could have



Cristen O'Neal at age 16.

more time to address unfinished IEP goals that had been identified. As a family we decided to allow Cristen to attend the school for the deaf for two years. So even after she received her first diploma from Cranberry High School we decided not to let her graduate; she went to the Western Pennsylvania School for the Deaf (WPSD) in Pittsburgh and graduated from there two years later with another diploma. I think that she really gained a lot more independence from the school for the deaf as she was only home on weekends. She also gained more self confidence in that she had many friends and more of a social life. After graduation from the school for the deaf, we knew that it would not be fair to Cristen to keep her at home. We realized that if she was ever going to have a chance of living on her own

someday, we needed to let her go back to HKNC for more comprehensive training. I explained to Cristen that she would always have *home* to come to, but that she needed this experience. Eighteen months later, Cristen was in her own apartment and living independently thanks to so many caring and supportive professionals. I recall one conversation I had with Cristen while she was at HKNC, living in her own apartment there, when she shared with me that she had taken the public bus on Long Island to a large shopping center all by herself. The thought of her out there by herself scared me to death. I know that had she not gone to HKNC opportunities such as this, for her to mature and be self assured, would never have happened because I would have been too frightened and selfish to ever let her do anything like that. I am so very grateful to all the professionals who worked with Cristen; my husband and I could not be more proud of her than we are right now.

If I had it all to do over, I don't know that I would have changed anything except that we may have sent Cristen to the school for the deaf sooner. It was fear of the unknown, and the fact that she would have been so far away that kept us from doing it

sooner. However, I am very thankful also, to all of Cristen's teachers at Cranberry, who also helped me to learn how to effectively communicate with my daughter. I know that if Cristen had started her schooling at the school for the deaf, I would not have been able to communicate with her as well as I do now. Also, she has a great sense of family, since we all spent so much time as a family learning sign language together.

Cristen's home school district – Forest Area – was very supportive from day one of her education because, I think, they knew that I would settle for nothing less. I attended and contributed to all of her IEP meetings. The school district provided all the adaptive equipment that was necessary for Cristen's education. They also were responsible for arranging for an extra interpreter in the classroom the two years she attended the school for the deaf. This helped Cristen a lot since, due to her poor visual acuity, she could not see the teacher well enough.

All in all, we could not be more proud of our daughter. She has worked very hard to get where she is at today. My future hope for Cristen is that she will meet that special person and start a family of her own. I know that she would also make a great mom someday.