

Meet Some Adults Who Are Deaf-Blind

Information About This Issue From the Editors of reSources

The editors are very excited about this issue of reSources. We think that the opportunity to hear from adults who have dual sensory impairments is important. We did not tell the authors what to write, but asked them to choose a subject which they thought that our readers might enjoy. You are going to find diversity.

I remember that when I first learned that my daughter had a multiplicity of challenges, one of the first questions in my mind was: "What kind of a future can she have? What will she do? Can she do anything?" Naive questions, but honest ones that we suspect many parents ask when they first learn their child has special needs. Back in the '60s my wife and I became involved in a national organization called Toward Rehabilitation and Inclusion Parents of the Deaf (TRIPOD). For the first time, we had an opportunity to meet and work with adults who had many of the same issues as our daughter. We started to see hope for the future. We saw first hand that people with special needs can be very productive members of society; but one must start planning for children with special needs early in their lives.

In retrospect, this was one of the best things that happened. As a result of that involvement we started a nonprofit agency called Deaf Action Group (DAG), which again brought us into contact with adults with special needs, professionals working in the field, and people in agencies. Again, a great help in planning for our daughter's future. Last July, at our third Summer workshop for T.E.A.M. (Transdisciplinary Education Assessment Model), to conclude our workshop on a Saturday afternoon, we held a Consumers Panel composed of five people with dual sensory impairments (and other issues). They shared with the participants what their lives were like and held the audience spellbound with the information they shared.

We hope that you find this issue equally exciting and informative.

Growing Up Deaf-Blind by Heidi Sherrie, Teacher's Aide

I was born on the island of Maui in Hawaii. Because of the worldwide rubella epidemic, I was born deaf and almost blind with a cataract in my right eye. When I was 18 months old the cataract was removed. They tried to insert a lens in the right eye but I would not tolerate people trying to jam something in that eye. My left eye had to compensate for the right eye which

resulted in the gradual deterioration of my right eye. I also had a severe to profound hearing loss in both ears which meant that I had some remaining residual hearing that could be put to use.

I was born the second child of hearing parents and have two hearing sisters. My parents were loving and understanding. They wanted the best for me. My two sisters accepted me. Unfortunately, on the island of Maui there were no services which could help meet my special needs. My parents then made the decision to move to Oahu where there were programs for young children with dual sensory impairments.

During my first year, my parents contacted the John Tracy Clinic for assistance, but quickly realized that an oral approach to communication was not going to work-especially with my visual problems. (I also had a nystagmus which later took two operations to repair.) Next I went to a school where they taught “cued speech,” but they quickly saw that it was not going to work. Two magic words, “total communication,” came into being about this time and this was used as the basis for my education. At the age of four I started attending Hawaii School for the Deaf and Blind (HSDB) with a total communication program. HSDB started a special class for four deaf-blind students taught by Miss Alice Unawai. Under her guidance for the next four years, I blossomed into a student who showed a natural affinity for language and reading. She showed me many things about life and allowed me to be my own person. Miss Unawai was an excellent teacher and is a lifelong friend.

During that time, I learned how to sign, and my parents, seeing the positive results in improving my ability to express myself, immediately bought the latest sign language book, “Signing Exact English” (SEE) and started taking classes. Every time I learned a new sign I would come home and teach the whole family the same sign. Within months, my family was signing. To make it even more fun, my mother would read me stories in sign language and then I would ask the family to act out the story. Also I started to take speech lessons and, with the help of a hearing aid (a box worn around the chest), my hearing was improving and my speech was becoming almost intelligible. By the time I reached high school (thanks to lots of speech therapy in school and privately) I was able to speak pretty well, and learned to use both lipreading and listening skills to be able to carry on a brief conversation with hearing people.

After four memorable years in the deaf-blind class, I moved on to a class with other deaf children my age. I stayed here for the next two years. In third grade my parents realized that the educational system at HSDB was no longer going to work for me. I was in a class with an outstanding teacher. She was pregnant and the doctor ordered bed rest for the rest of the pregnancy. The school brought in substitutes who had no experience working with the hearing impaired. Every week we had a new sub. My parents knew it was time consider a move to the mainland where better educational opportunities were offered. In the Fall of 1974, I went with my parents to California for a week to tour three schools that supposedly offered excellent programs for the hearing impaired. At the end of the trip my parents sat down with me and asked which school I would like to attend. In my opinion, Taft Elementary School, located in Orange County, was the best. The next Summer, my family moved to a new home in Santa Ana just across from Taft Elementary. For the first time in my school life I did not have to spend two hours a day on the bus.

The adjustment to the move was not so bad as I made new friends with other children who were hearing impaired at a Summer camp for the junior blind. Some of them also attended Taft. In the Fall I was placed in a deaf class with a deaf teacher. “Mainstreaming” was then the “in” approach. One memory stood out: this was my first experience being a member of a fourth grade hearing class for reading with an interpreter. The next year, I was placed in a gifted class for deaf children and the teacher was one of my favorites as she breathed fresh ideas and gave us fun projects to challenge us at every turn.

I went on to intermediate and high school where I was mostly mainstreamed but sat in on some of the self-contained classes such as math and driver’s education. I did very well academically and had a fairly active social life. One new development came up in the Summer when I was thirteen. I had a grand mal seizure for the first time. I now had to start taking medication daily to control the seizures. At first I sort of denied that I had a seizure problem and often forgot to take the medication. Gratefully, every seizure I had always happened at home so none of my friends knew about it until I went to Gallaudet College in Washington, D.C.

I went to Gallaudet for two years, but had to leave for many reasons-mainly because I was not getting enough support from Gallaudet. I returned home and attended the local community college for the next eight years and managed to complete most of my liberal arts requirements, but no college degree. I did dream that someday I would get a BA degree and that was my goal no matter how long it took. Also with new medication, I was able to stay seizure free-which I still am.

Adjusting to the real world as a deaf-blind adult was gradual and it became easier to come to terms with my limitations such as transportation, social life, work and schooling. I was not able to drive, not just because of my vision but also because of poor coordination due to mild cerebral palsy. I had to learn to ride the bus. At first I made many mistakes but I learned to get around. Of course there were limits to the bus service which meant I couldn’t go out to social events as much as I would like. I did have several friends, but I felt I would be imposing on them too much.

When I came back from Gallaudet I lived with my parents for a few years. Finally, they came to their senses and told me that it was time for me to move out on my own and learn to be independent. It was scary at first, but Mom and Dad helped me to find a roommate and a place to live. Previously, I had learned to pay the phone bill and credit card but now I had to learn how to pay rent, go to the store for food, and take the bus across town to the college. I also learned to make decisions on my own, sometimes resulting in making mistakes; I learned from these experiences, allowing me to grow into a mature and independent adult with responsibilities of my own. I knew that my parents would be available to help me with any financial crisis no matter how big, but I made sure that it didn’t happen often as I was too proud to admit that I needed help as I lived from one SSI check to the next, month after month.

I lived with three different roommates at three different locations. Each time I moved to a new address, I was able to settle in quickly and learn to abide by the roommate’s expectations and to

help make a contribution to the maintenance of the household. Sometimes it is not easy living with someone but I made it my rule to respect and tolerate their differences.

I knew many men but I didn't date much since I did not socialize as much as I wanted. I didn't honestly think I would meet someone I could really enjoy being with or who would respect me for who I am. In the beginning of 1992 I had the strangest feeling that I would meet someone that year. It so happened that one of my closest friends, who was also deaf-blind, announced that she was being married that Summer and I was asked to be in the maid of honor. She had also asked a good friend of hers, a man she met at Gallaudet (who has Usher Syndrome) to be in the wedding. I flew to Dallas two weeks before the wedding to help my friend make preparations. When I arrived, she told me about her friend, Tim, but I didn't really think he was the man for me from what she told me. Six days later, I got to meet Tim in person and he turned out to be a sincere and a very funny person. For the next few days I got to know him and found out that we had a great many things in common. When we left Dallas to fly to our homes in different states, we decided that we would write to each other-which we did. We talked on the phone and wrote for nearly nine months before I went to visit him in Denver during Easter vacation. I met his family who warmly welcomed me. Then I made the decision to move to Colorado.

After moving to Denver, I managed to get employment with a temporary agency specializing in printing. We lived in a one bedroom apartment and decided to move to a better neighborhood and a bigger place. Then I lost my job. Tim was working full time for a fast food restaurant and with only my SSI, it was a bit tough to make ends meet. In January he proposed marriage which I accepted wholeheartedly, and we made plans for a wedding in 1995. Both of our families were happy for us and supported us all the way.

Fed up with the temporary agency, I went to vocational rehabilitation and asked for help. They recommended that I contact an organization called Center on Deafness about their new training program which had been implemented just a few months before. I took a tour and decided to register for classes. It was a 15 week program. The best feature of this program was learning computers and all the software necessary for an office job. The program was run and taught by deaf teachers. I made many new contacts as it was discovered that I was a bright person and could be a valuable asset to the deaf community. For example, I was hired for a short time to tutor two deaf women. Later on, I got part time work for an agency that serves people who are developmentally disabled. I was recently hired as a teacher's aide with the deaf program at a local elementary school.

Planning for the wedding took us a whole year, and we could not have done it without both of our parents' help. Eventually, we chose a church, a reception site, took care of numerous details and underwent premarital counseling with an interpreter present. For me, marrying a man who has Usher Syndrome was not really a big deal, since I was attracted to him in many ways. We are now making preparations for when he totally loses his sight, and are trying to find out as much as we can about Usher. The wedding went beautifully with about 85 of our relatives and friends attending. It was truly a celebration.

For the future, I plan to return to school to take courses to obtain a degree in human services; I

have a strong desire to work with the deaf community, especially with deaf-blind people. There is a desperate need to improve services for the deaf-blind who live in Colorado in areas of social, support services and employment.

To sum it up, I can tell you that as a deaf-blind child of hearing parents, the most important things I received were love and patience. They accepted me as an individual, listened to my feelings, advised me on emotional issues and allowed me to build self-esteem in my teenage years. As an adult, they have supported me in major decisions that I have made. Also they encouraged me to use my best talents such as art and writing to boost my self-esteem. As I look back I am most appreciative of my parents who raised me to lead a satisfying life as a deaf-blind adult.

I'm an Adult In Transition
by Cathy Mouchka, Graduate Student
California State University, Sacramento

Several months ago I wrote an article for reSources on my experience as a student in the regular education classroom. This article is a follow-up to that article, and focuses on my experiences as an adult making the transition from school to work. During the last few years, I have been a person with hearing and visual impairments going through transition from school to work. In fact, I am going through transition twice! My first transition was when I graduated from CSU, Sacramento in 1988 with a Bachelor of Arts in Communication Studies. My second transition will be when I graduate from CSU, Sacramento again in 1996 with a Master of Arts in Education and Special Education.

Transition, for me, has been a time of change, exploration, anxiety and at times, a "bumpy ride." When I graduated in 1988, my parents gave me three choices for a graduation gift. One choice was a down payment on a small condominium. I chose the down payment on the condo because I felt that I would be more secure on my own if I had a home I owned. To help pay for the condo, I began a full-time paraprofessional-level job in the Community Services Section at the Franchise Tax Board, a job found by family friends.

That first night in the condo was lonely with my parents down the street and myself alone with my hearing and visual impairments. Fortunately, I had a friend in the same complex and I had her visit me. My parents helped me with major grocery shopping and I soon used the stores near my home for almost daily grocery trips. Days were busy with work, and eventually I looked forward to coming home to my "retreat" to sustain "life." I made contact with neighbors, other friends, the community, and, of course, was in contact with my parents.

I had plenty of State support in my first job with Community Services at the Franchise Tax Board. I was in a Limited Examination Application Program (LEAP) placement and my salary was paid by the Career Opportunities Development (COD) program. Eventually, I was picked up from permanent-intermittent status to permanent-full-time status as an office assistant with the Statistical Research Section at Franchise Tax. Although I had permanent-full-time status with the State, a feat, given the competitiveness of State service, the job was a trek off the career path for

me. For three and a half years I attempted to network for other job opportunities while “working” boxes of tax returns used for tax research.

Although I was “paying dues,” my dues paying turned out to be worth it. In 1990, when the real estate market was exciting, I was able to sell my one-bedroom condo for full price and buy a two-bedroom condo for below price. I revelled in being called a “real estate tycoon” and decorated my new home with pride. A few years later, I continue to be happy in my larger home and spend many hours working in the second bedroom-now my study.

A couple of years after my move, the same family friend that helped me find my first job told me about a lateral transfer to the School Partnership Program at the Franchise Tax Board. Eagerly, I took the job, excited about the opportunity to work in a “human interest” area and with schools. In the job, I helped develop the program, prepared for program events and made liaison with people participating in the program. Yet, I was unsatisfied. I was still an office assistant with a college degree and I wanted more.

In addition, I had experienced some daunting discrimination in this job and the one before it. In one job, when I let callers know I was hearing impaired, my supervisor said she was not comfortable with my letting them know. She was also wary of my having a speaker phone device installed on the phone to help me hear. In another job, my supervisor kept me from attending an event others attended because she felt my hearing and vision would pose problems. My feelings of needing to somehow “move on” were again reinforced.

Mentoring a student with learning disabilities beckoned me to a teaching credential and a Master of Arts in Education. My goal was to become a Resource Specialist working with students having learning disabilities. The State allowed me to go on permanent-intermittent status again as I worked part-time for a while, then did not work at all for several months. Financial aid helped during those months as I was a student teacher in several public schools and spent seven-days a week studying. I found working with children to be both a joy and challenge. Some good successes came to me in one-on-one and smaller group teaching. Sadly, during my regular education student teaching, I learned that my dual hearing and visual impairments would pose challenges to my becoming a credentialed teacher. Without adequate modifications, I was unable to teach thirty children at once in a classroom. Thus, I am prohibited from obtaining a special education credential because I am not first able to obtain a regular education credential. Now I am pursuing a Master of Arts in Education and Special Education only.

While I was beginning my graduate program, I was transferred to the training section of the Franchise Tax Board, and now have a job I enjoy. This job is still at the office assistant level, but the people I work with are creative and hard-working. There is recognition that I can do many things, and I am given more varied, complex assignments. I have been provided with the modifications and equipment I need to do the job well, including a telephone volume control and a signal light to let me know when the telephone is ringing.

At this point, I plan to stay and find out if I can establish a career as a Training Officer teaching career and work skill development courses. If this is not possible, I plan to research and search

the Sacramento area for work in any field that is of interest to me. I have also considered working as a private contractor in educational consulting and therapy, but realize my hearing and visual impairments could pose challenges to developing my credibility. At this stage in my transition, I am keeping my options and eyes open. In the meantime, my life is full of activities, including bowling in a weekly league, Junior League activities, being with my family, and serving as a member of the California Deaf-Blind Services' Advisory Committee.

Sharing

by K.C. Spear, M.A.,
Counseling and Guidance

As I considered how to approach this article, it seemed that it might be helpful to examine some facets of the life process for deaf-blind children living today as compared with those experienced by my generation. For example, there was no support system for my family. All too often, the stigma of having a disabled child resulted in feelings of shame and rejection. Additional advantages for today's generation include: advances in medical science and the availability of sophisticated optical and auditory devices that enable a child to utilize residual sight and/or hearing. There are some assistive technological devices that enhance communication, mobility independence such as Lite Touch, the Polaron and Vibra-Call, and the computer with features like the CD-ROM, Internet, etc. that make acquiring an education (as well as employment) easier. At the same time, although the "Electronic Age" can go a long way toward minimizing the sense of isolation inherent in deaf-blindness it should not become as Braille books were during my adolescence—a substitute for human companionship. The preschool years had a profound effect on my development. At 18 months I was fitted with glasses and, with my right eye only, could see colors, identify people and get around the neighborhood without assistance. I began walking at the age of two, but communication was a problem. With a growing family, it was easier for my mother to let me "run wild." Church on Sunday was another important part of my early years. Like my siblings, I began accompanying my parents to Mass during infancy. Obviously, not until much later did I grasp the concepts of Christian doctrine. However, I looked forward to the time each week when I sat quietly amid the smell of incense, candles and unhurried movement, engulfed by a sense of peace. Until the verdict of deaf-blindness became conclusive, my Dad took pride in teaching me the fun things of childhood: bouncing a ball, using playground equipment, swimming etc., and he encouraged me to explore my environment. Dad also helped me to see the funny side of life. Summarily, despite the rejection I experienced later, my parents gave me three invaluable gifts: faith, freedom and a sense of humor.

As a consumer with training and experience as a professional in the field of deaf-blindness, I feel qualified to state that, given the current lack of funds, trained personnel and limited peer contact in most school districts, I feel that the decline of the residential school was unfortunate. It should be noted that I was enrolled in four different day programs before I entered a residential school. Some of the benefits I experienced in the residential system are listed here.

1. Test books and Regents examinations were available in Braille, and the school housed a good-sized library of Braille books with fiction and nonfiction titles. Consequently, I was expected to cover the same course material as my sighted peers and to complete assignments on time.

2. I learned to communicate with the Manual Alphabet (also called “finger spelling”), with English as my primary language.

3. Teachers in the Deaf-Blind Department knew how to communicate and there was daily interaction with other children who were deaf-blind.

4. There was ample opportunity for physical exercise both in fully equipped gym and track and a playground. We were encouraged to move freely from building to building and to take part in outdoor activities such as skating.

5. Children were not only responsible for personal appearance but expected to keep their living space in the dorm neat and tidy and to practice good table manners. My independence was further encouraged during month-long sessions at summer camp. Although I knew the meaning of loneliness at an early age, the teen years were especially difficult. Like any teenager I wanted a social life with parties and dances. Such events were planned for by students who were blind. By age 15 I was totally blind, so then I became more dependent upon the kindness of others to reach out to me. That seldom happened at school social events. I have to admit that, until I went to college I was unaware that I could be accepted for myself, or that I might know the fulfillment of a career or marriage.

In conclusion, there are certain qualities that are important to anyone, but even more so to those of us who are deaf-blind. In my estimation the most important are: a belief in God as well as a belief in oneself, the ability to communicate, and the desire for and tools to achieve independence and a sense of humor. I have often found comfort in poetry and one which I find helpful reads, in part:

Success is failure turned inside out
The silver tint on the cloud of doubt
You never can tell how close you are
It may be near, tho it seems so far
So stick to the fight when you're hardest hit
It's when things look worst that you must not quit

Attitudes

Cristi Saylor

Teacher, Los Angeles Unified School District

It's difficult for me to know where to begin to tell anyone about my experiences as a person who is blind in one eye and hard of hearing. In a sense it all seems so far away. It seems that the difficulties are a thing of the past. I feel almost as if I got over it. In a sense I did. I learned how to adjust the world to fit me, and how to adjust to it. My disabilities are a way of life rather than some overriding part of who I am. I remember the first time it really hit me that I saw differently than other people. My brother, sister and I were looking in a children's magazine that had some optical illusions. I couldn't do one of the illusions. My brother and sister kept insisting that I try

again and again, and still I couldn't do it. We then went to our parents and my dad explained that the optical illusion required two eyes. This news surprised me. Until that moment I had known that I saw with one eye, but that it meant anything never really hit me. Throughout my life I have had several kinds of experiences in which I discovered how I see or hear differently. It makes me wish I had known someone similar to me who could have shown me this rather than discovering it over the course of many years.

While growing up, I felt as if there were many things I couldn't do; in retrospect I think it was partly believing what I was told, and partly needing more time and a different approach to accomplish my goals. One person, a driving instructor, did show me little "tricks." I tried several times to learn to drive, and gave up after each try. I decided to try again after meeting a man who had lost his hearing in one ear. I told him the reason I didn't drive. He commented that it didn't seem like such a big deal and suggested that I would just need to do things in a different way. That marked the beginning of a new attitude for me-finding my way of doing things rather than trying to do things the same as everyone else. One of the cruxes of having a disability is finding your own way, and allowing others to assist and support you. It is through the attitude of creative positive thinking that this becomes possible.

As Joseph Shapiro wrote in his book, *No Pity, The Civil Rights Movement of Disabled People*, we, disabled people, want neither pity nor overblown admiration; we want to become part of society. Attitude is the key to accomplishing this. Overall, it has always seemed to me that the attitudes of others, and hence my own, were the struggle much more so than my disabilities. Learning some things has been frustrating and took more time and effort than might have otherwise been required. At times this has made me feel angry or annoyed. I wouldn't be human if I never felt these things. The times that stick out in my mind relate to attitudes-either the times when I was laughed at because I couldn't do something or the times when someone helped me figure out how I, too, might do the "event" of the moment.

The positive creative attitude, on my part and others', has opened doors to my becoming another member of our society.