Dealing with Hearing Loss

by Diana Ramsey

(I received this email from Diana Ramsey. Diana lives in Hurricane but was born and raised in Elkview, West Virginia. I thought that it was so good about what it is like to be hard of hearing, that I wanted to share it. I asked Diana if it would be okay if I shared her story and she gave me her permission—Newsletter Coordinator).

My name is Diana Ramsey. The recent July 2006 newsletter arrived today and I immediately sat down to read it. Your article “If You Can Speak Well, You Can Hear Well, Right?” really hit home with me personally so I had to sit down and compose this email to you.

I, too, am hard of hearing from birth, although for the vast majority of my life (I am 46) no one in my family (or doctors) were sure whether I was born hard of hearing or became so in infancy from ear infections. My mother said that I had a lot of ear infections, many of them serious that resulted in bealed ears and a busted ear drum. About 8 years ago, I learned that I was born hard of hearing and it was genetic due to Waardenburg Syndrome (WS).

My mother was born with the "white forelock," a very distinguishing mark of WS. I have an aunt, cousins and niece who were born with one eye having two different colors, half blue and half brown, which is also a classic sign of Type 2 WS. Since none of us knew anything about WS (until I found out 8 years ago) we never connected the interesting "birthmark" in my mom's hair to the oddly colored eyes and my hearing loss. There also were no audiologists or eye doctors who "connected the dots" and figured out that we all had WS.

My parents did notice, as I learned to talk, that there must be a problem with my hearing. I did not have problems with every word but my parents noticed that I did not have a "speech impediment." They took me to audiologists and doctors but no one offered my parents any suggestions.

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Personal Stories: “The Miracle of the Cochlear Implant!”

by Janean Oliverio

One cold evening a missionary arrived at our door selling books to raise money for her tuition. I invited her in. My son, Broc, was very excited to have company. She inquired, “What is that on his head?” I shared with her that he was born deaf and we chose a cochlear implant for him so he could develop spoken language.

Broc heard me speaking of him and he decided that he wanted to “tell the story.” He explained to our visitor, “When I was a baby, I was in my mom’s belly. When I came out of her belly, the doctor said my ears were broke. He said I had to have a surgery to get a cochlear implant so I can hear, and now I can speak Spanish.”

So thanks to the miracle of the cochlear implant and Dora the Explorer, my son is very verbal in English and Spanish!

“I think you always keep that initial feeling of pain when you find out your child or children are hearing impaired and that is okay as long as you don’t dwell on the pain and miss out on the wonderful masterpiece of a child that is right in front of you.”

-Diane and Tom Miller from “Journeys with Our Children”

Spotlight on The Family Support Program

Any family who resides in West Virginia and has a person living in their home who has a developmental disability is eligible to receive available services through the Department of Health and Human Resource’s Family Support Program. The program is available regardless of income or the age of the person with the disability. Program funding for services may be available after all other resources are explored.

How did this program help my family? We had mounting doctor bills after Becca’s diagnosis (newsletter coordinator Melinda Siler’s daughter). We could not afford to pay them all. I found out about Family Support Services from the Birth-to-Three program. I filled out an application that was presented before a council who reviewed and made a determination based on available funds. They approved our application and allowed us up to $1,000 toward our doctor bills. This was a HUGE help and alleviated a lot of added stress to our family.

What can I apply for help paying? ANYTHING! Anything that will help improve your family life. It will help pay for anything that other programs or organizations cannot help pay. For instance, another family with a young hard of hearing child lived in town with the street directly in front of their house. They had problems with their child leaving their yard. They were afraid the child would get hit by a car. They needed a fence around their yard to keep their child safe. The family applied to the Family Support Program and they were approved. The program helped the family pay for the fence.

To locate the nearest Family Support Program call 304-558-0627 and ask for Cassandra Toliver, the State Family Support Coordinator or visit their website: www.wvdhhr.org/bhhf/famsupl.asp. You can also write to them at The West Virginia Family Support Program, 350 Capitol Street, Room 350, Charleston, WV 25301.
Thank You for a Wonderful Year

by Melinda Siler, Newsletter Coordinator

Wow! It has been one year since I first started this newsletter. Time really seems to fly, doesn’t it? I remember going to Deanna (Stone, Executive Director for the Commission for the Deaf and Hard of Hearing) and pitching my idea for a newsletter. I told her that I thought it would be a good way to reach parents, especially those in rural areas. I remember telling her that there are a lot of wonderful programs and organizations out there to help families with deaf or hard of hearing children, but there is really no good way for parents to find out about them unless they happen to stumble upon the right person. Deanna agreed. She felt that a newsletter would be a good idea. There was one catch, though. She asked if I would be willing to write it and take it as a personal project. I’ll have to admit, I was taken aback. I am not a writer. But I was afraid that if I didn’t say yes then the newsletter would not become a reality. So I told her that I was willing to do it.

I began piecing together a newsletter with Molly Simonton’s help. (Molly is the Deaf and Hard of Hearing Project Director at Marshall University Graduate College). She is my sounding board and resource person. I took me about a year to get it all together (just working in my spare time) but I finally created a copy that I could present to the Commission for the Deaf and Hard of Hearing board members. I was so nervous! It was voted on and it passed! The Commission agreed to take on the cost to print it and mail it for me. I was so excited! Next it went to the Department of Health and Human Resources where it was proofread and then on to the presses.

It has been a wonderful year writing this newsletter. I would like to thank Deanna Stone for giving me the nudge I needed to take on this project. I also want to thank Molly Simonton, Kari Preslar, WVCDHH board members and DHHR.

A big thank you goes out to all of those people who have contributed throughout the year with stories, advice, information and so much more. If not for your stories, I would not be able to keep the newsletter going. Please keep writing. If you have already sent me a story, than send another one. I know there are many stories to tell, and you could possibly help someone else who is experiencing the same problems. Thanks again to all of you. I am looking forward to another great year.

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TIP CORNER: A Guide to the Individualized Education Program

The purpose of this guide is to assist educators, parents, and state and local educational agencies in implementing the requirements of Part B of the Individuals with Disabilities Education Act (IDEA) regarding Individualized Education Programs (IEPs) for children with disabilities, including preschool-aged children.

What if parents don’t agree with the IEP?

There are times when parents may not agree with the school’s recommendations about their child’s education. Under the law, parents have the right to challenge decisions about their child’s eligibility, evaluation, placement, and the services that the school provides to the child. If parents...
help. I am not sure why. Maybe I was not hard of hearing enough to merit help in their opinion. I
don't know.

But I do personally remember entering the first grade (there was no Kindergarten at that time)
and the school health nurse gave us all hearing tests. She had a little box with a couple of knobs on
it and a set of headphones. She instructed me to turn with my back to her and with the headphones
on and I should raise my hand if I heard anything.

I remember hearing the first "beep." After that nothing. The nurse became rather excited and
repeated the test, with the same results. She sent a note home to my parents because she was
concerned about my obvious hearing loss. But again, there was no assistance offered by the school
system or the state to me or my parents. Again, I do not know why.

Was my hearing loss not serious enough? Since it seemed to everyone around me (in school and
public) that I could hear "well enough" and I voiced well and I seemed to function well, then maybe
the "professionals" thought I would be "alright."

I remember another occasion at the Audiologist when I was a teenager. After my hearing test,
he told me there was nothing he could do to help me. He said that when I was in a crowded room I
should stand with my back against the wall so the sound would bounce off the walls to my ears.
What were my parents and I supposed to do? The "professionals" offered no help. So, it was just
something I had deal with.

So I went to school and despite no hearing aids, no speech therapy and no accommodations for my
hearing loss, I did remarkably well. I was a straight A student all through school. I am pretty
proud of that accomplishment. I loved to learn and I still do. I became an avid reader and reading
helped me to understand better what was being said. Many times, once I see how a word is spelled,
then it helps me to understand what is being said. I understand the letters that I am hearing wrong
so I can correctly pronounce the word. I do rather well with words and names I am familiar with
but have trouble with new names and words, until I see them spelled.

My parents were a big support to me. They always helped me pronounce things correctly. My
mother would ask each new teacher to sit me up front in the classroom. Unbeknown to me, I was
doing just as your daughter does (Melinda's daughter, Becca). I was reading lips and body language
and I filled in the gaps from environmental clues. I do that to this day, but now I know and
understand what I am doing. I still don't concentrate on doing it. It is just part of who I am. It is
acquired "survival skills."

Now you know a little about my experience so when I read your article, I thought, "Oh, how true."
Many people I have grown up with or worked with were surprised to learn that I am hard of hearing.
I am told that I do not have a "deaf/hard of hearing" voice, so how could I be hard of hearing?
Also, because I have a mild hearing loss in the low pitch and a moderately severe hearing loss in the
high pitch, then there are certain voices and sounds that I can hear better than others and some
things I cannot hear at all. People have accused me of "hearing what you want to hear" or "how can
you hear that but not hear this?" And just like your daughter, quiet rooms and one-on-one will make
a BIG difference in our hearing "ability," compared to noisy restaurants, school lunch rooms, out of
control classrooms, family gatherings, etc.

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But I understand the ignorance of the hearing world about those of us that are hard of hearing or deaf. I, too, was ignorant, as was my family, despite myself being hard of hearing. The so-called “professionals” in the world of “hearing problems” did not educate us. So it is understandable that the hearing people out there are definitely “in the dark.” Yourself, for example, would you be “in the know” about hearing loss and its impact if not for your daughter?

There came a point in my life that I wanted to know more about myself. About 8 years ago I enrolled in the ASL Classes at the West Virginia Rehabilitation Center. I not only started the process of learning ASL but I also started on a journey of discovering myself. As I learned how a hearing loss (from mild to profound) can and does affect a person and how that hearing loss shapes the person into adopting adaptive behaviors, there emerged a better understanding about myself. I have always been told how observant I am.

People say, “You don’t miss anything.” Well, maybe it is part of my in-born nature. If information is blocked from entering the brain through the ears, it must be picked up some other way, such as through the eyes. Humm, so could my increased skill of observation be due to my hearing loss? Very likely.

Also around that time, I decided to go to an Audiologist for the first time since my teens. I had no record of my visit in my teens so I had no idea what type of hearing loss I had. As I stated, my biggest problem is in the high pitch range. Both ears are almost identical with a moderately to severe hearing loss. At that time I was told that it was unlikely that the type of bi-lateral hearing loss I had occurred from ear infections. By that time I had learned about WS and the two together was more than enough proof that I was born hard of hearing and that it was genetic. I got my first pair of $3,000 hearing aids, which my insurance would pay not one cent, ha ha!

WOW! What I have learned in these few short years. I now have become involved with a group of people that understand what it is like to be hard of hearing. It is very likely that I will be deaf someday but I feel even better prepared for that than ever. I have adopted ASL as my own. It is a beautiful language and one that I wish I had been given the opportunity to learn from childhood. But “old dogs can learn new tricks,” and I plan to keep on learning as long as I live.

I am sure your daughter will do fine. She is fortunate to be born into this generation. So much is being done to help children now with all degrees of hearing loss, from mild to profound. Deaf awareness is becoming much more widespread. She is also very fortunate to have you on her side. As long as you continue to put the information she needs there for her to understand, whether through her ears with hearing aids or through ASL or lip reading or all the above, the important thing is to be there for her.

I have learned to “speak up for myself.” I am not ashamed that I am hard of hearing; it is who I am. I am very willing to educate the hearing public, just as I had to educate myself.

So tell Becca to be proud of who she is and do not be afraid to say, “I am hard of hearing; can you speak up please; can you look at me when you speak.” Her self-esteem will be one of the most important things she possesses. I hope someday I can meet you and Becca. In the meantime, keep writing your wonderful articles.

Diana Ramsey
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disagree with the school’s actions (or refusal to take action) in these matters, they have the right to pursue a number of options. They may do the following:

First: Try to reach an agreement.
Second: Ask for mediation.
Third: Ask for due process.
Fourth: File a complaint with the state education agency.

For additional information see: http://www.ed.gov/parents/needs/speced/iepguide/index.html.