

"How to Raise Deaf Children"

Presentation given by Bronwyn O'Hara on October 22, 2016 at the Primary Children's Hospital--guest speaker forum for the Social Workers working at the hospital.

I want to thank you for inviting me and Stephanie Mathis to speak with you today. It's a privilege to talk with you about raising deaf children.

Before I get going let me explain some acronyms:

ASL=American Sign Language

USDB=Utah Schools for the Deaf and Blind

PIP=Parent Infant Program

JMS=Jean Massieu School for the Deaf

IEP=Individual Education Plan

LSL=Listening and Spoken Language

LEAD-K=Language Equality and Access for Deaf Kids

Child with hearing loss=this means children who are deaf or hard-of-hearing. Believe it or not, these children have the same needs

Family Background:

I have a deaf husband. He wore a hearing aide and spoke. I thought hearing aides restored hearing like that of a hearing person. That's a common error. Hearing aids did not make him hear like a hearing person.

It turned out our family had a genetic predisposition for deafness. Our family has the B-O-R Syndrome and this is what caused our family's hearing loss. B stands for Branchio; O stands for Oto; and R stands for Renal.

This gene has a 50% chance of being passed on to the next generation from one who has the gene. The gene is an autonomic dominant gene. A mutated gene can also be created that can pass on the condition.

We had 3 children with hearing loss out of our 7. That's about 50% (list them on my hand and indicate which are deaf and which are hearing) = deaf, deaf, hearing, hearing, deaf, hearing, hearing.

I want you to understand the frustration I felt as I learned the things I'll be sharing with you. I learned them a little at a time. I'm happy to share what I found out about raising children with hearing loss, if I can save parents time and frustration.

What did I learn?

My husband was the only deaf person I knew. He had grown up in California in a listening-and-spoken language program. For the first 10 years of our marriage, we lived in 5 different states. That was not long enough to get to know the local Deaf Community. I relied on my husband's advice and used the listening-and-spoken language format with our oldest and second oldest children. My husband had been told as a child that to use sign language meant failure. He was severely discouraged to sign.

As I worked with my oldest deaf child, I could see her mounting frustration. It was easy for me to give verbal commands but, at 10 years old, she was old enough for discussion and I couldn't discuss anything in depth. I wasn't connecting with her, emotionally. I saw her frustration and sadness at being left out at the public school: Quiet children were ignored while more assertive children became angry and disruptive. She was not a quiet child.

I felt something was wrong. I didn't know it at the time but we needed a visual language.

I came into contact with several helpful resources that help open my mind to sign language:

1. Through the Idaho School for the Deaf I listened to a cassette tape that had been made to show what it sounded like to have a hearing loss. I was shocked at the gaps in listening to speech. It was like a cell phone cutting out. It was impossible to tell what was being said. (And I expected my deaf child to ?)

That cassette tape made me curious about what sounds came into a hearing aid. What did it sound like ? I put on my husband's hearing aid and couldn't believe the terrible noise coming through ! I couldn't believe that I expected him (and our children with hearing loss) to hear speech through all that noise. How could they tell what was being said ? I became convinced that hearing aids do not restore hearing as that of a normal hearing person.

My mother-in-law gave me a book called Deaf Like Me. It was written by a father who chooses to sign with his deaf daughter. This book opened up my mind to sign like nothing else. It showed me I could have real conversations with my children. It showed me that deaf children could learn like hearing children learn. I was fascinated by a conversation recounted in the book where the 4-year old deaf child answered her dad with "Maybe". That was monumental that such a young deaf child had that ability to answer like that. I wanted my children to be able to think like that. I wanted my children to be able to discuss like that. And yes, I wanted my children to be able to disagree with

me like that.

I hit a turning point when my oldest was about 10 years old. She was setting the table across the room from me. I told her something about beets. She thought I said meat. I started getting angry at her for misunderstanding me but then I realized those words look the same on the mouth and either one could have been right given the context. You try lip-reading these two words. Turn to your neighbor and soundlessly say those words. They look the same on the mouth.

It hit home that I was expecting her to do something I could not do= perfectly lip-read the English language! How unfair was that ?. Why would I do that to her ? I learned later that only 30% of our words can be seen on the mouth. That's a recipe for failure right there.

Right then I knew something had to change.

What did I do?

I decided that I wanted our family to switch to sign language. A visual language seemed much more compatible for family members with hearing difficulties.

At the time, we had a new baby identified with hearing loss. We were living in Idaho at the time so I asked for PIP advisor who could sign. I was told they had none. I couldn't believe it ! No one who could sign from the state deaf school to come into my home to teach our family to sign ?

Mary Dunne came to our home and later, Darlene Allen. We were there for 2 years, without making any progress to learn sign language. We heard about a deaf church group in Provo, Utah where deaf people were the members and everything was done in sign language. We decided to move to Provo.

You can imagine the difficulty a child with hearing loss would have in trying to make sense of conversation around him in the home or at school. It would be hard to be part of a discussion if they only had use of ears which didn't work very well. While attending the deaf branch of the Church of Jesus Christ of Latter-day Saints in Provo, I was told that persons with hearing loss can never become hearing but hearing people can learn to sign. I understood that I could learn to sign as a way of providing my children with what they needed.

Our youngest deaf child was 2 when we moved to Utah. I asked the Parent-Infant program director at the Utah Schools for the Deaf for a PIP advisor who could sign. They had no one who could sign. I couldn't believe it ! Another state deaf school without signing PIP advisors ! Dixie Welch, who was assigned to our home, grilled me about the wisdom of signing but, in the end, she supported our family learning sign language.

We began signing on the baby-level. It was perfect with a 2 year old and me and

our family could learn along with our toddler.

My personal goal in having our family learn sign was to not leave anyone out of conversations. We set up a system of signing and speaking everything. It helped us learn sign as a family and helped us slow down to communicate.

Communicating in sign and voice had to be done separately. The Deaf community in Provo helped me understand that you can't talk and sign at the same time. They taught me it's two different languages. You can't speak Spanish and English at the same time so don't try to sign and speak at the same time. I read research studies that corroborated this. Studies showed that if a deaf person was simultaneously signing and speaking, their dominant language (sign) would take over and the acquired language (spoken English) would become come out in pieces. If it was a hearing person doing that, their dominant language (spoken English) would take over and they would 'drop' their signs until the message was unrecognizable on the hands.

The study that showed this most effectively was done at a deaf school that used Sim-Com (Simultaneous Communication). The teacher was hearing and telling a story about the Easter Bunny. The researchers turned off the volume and studied her signs. She told the story of an Easter devil who had eggs and were coming to get them ! Good proof not to talk and sign at the same time!

Language: My children needed language

Instead of one overall Sign Language, I came to realize that USDB used various sign systems. I wanted to find out about them. I had a friend in Provo named Minnie Mae Wilding Diaz (MM). Maybe you've never heard of her but she is a third generation deaf woman who is well known in the Utah Deaf community. She is intelligent and well read on Deaf Education issues. She became my mentor and a role model for my deaf children. I wanted my children to be smart like her.

MM explained the differences between all the sign systems that were being used in deaf schools across the country. This was during the early 1990's.

There was Signing Exact English (S.E.E.), Conceptually Accurate Signed English (C.A.S.E.), and Pidgin Signed English (P.S.E.). SEE was used the most in a school setting because it had been invented expressly for teaching English to deaf children. Each of these methods are not 'language'. Their use confused deaf children.

In SEE signing, only one sign is assigned to an English word and it could not be changed. The procedure was that any time that particular English word was used, only that sign was used to represent it, regardless of the meaning of the English word in the sentence. For example, take the sign 'run' as in someone physically running. 'The boy will run home.' That makes sense. But then switch to another meaning of 'run' as in "The man will run for town Mayor." and then switch to another meaning of 'run' as in "My nose will run if I'm near cats." In each case the sign that was to be used with the

English word 'run' was someone physically running. Can you see how confused the children would become? To me, this kind of confusion was unacceptable. I felt it would be impossible for my children with hearing loss to learn English in such a system.

I learned from Minnie Mae that there was only one signing language that the brain perceived and processed as language. The brain is primed to learn through a real language not a made-up signing system. This is American Sign Language. I also found out that many deaf schools did not permit this language at their school as the language of instruction. My child's USDB program director told me why it was not permitted. The educators were afraid that, if the teachers used ASL in the classroom, the deaf child would not learn English.

By this time and with all the evidence piling up, I was convinced that ASL was the only way my children with hearing loss could get a real education. I wanted them to think, discuss, and make their own decisions. I began asking for ASL at our IEP meetings, the place where educational decisions were made for the coming year. I was told 'no' repeatedly. I brought in studies and research to show the benefit of using American Sign Language in the classroom. But no other parent was requesting this and, honestly, USDB didn't have the personnel to accomplish this.

I was feeling pretty desperate. My children's learning years were passing quickly away. I felt I had to do something more. I contacted the Legal Center for the Handicapped here in Salt Lake City. I guess now it's called Disability Law Center. I met the lawyer there and asked if I could make USDB provide language for my child. What was being signed in the school was not language and I felt this put my child at an educational disadvantage. Her hearing peers in the public schools were taught via a language. My child with hearing loss should have access to language, a language uniquely matched to her hearing loss. The lawyer explained he only handled discrimination in the work place and it would be hard to sue a school on a language issue. It had never been done.

At the time it was intimidating for parents to come against the school system. It seemed we had no support legally for our cause and no money to pursue it. I don't know if parents are more assertive now but back then it was scary to think about taking on USDB.

We could see that Utah was over-focused on the medical view of deafness so we asked the Deaf community which state deaf school in the nation was number one. We sent our daughter to the California School for the Deaf-Fremont for 2 years where ASL was used in their classrooms. She was back in Utah for her 4th grade year and nothing, I mean, nothing had changed at the Utah Schools for the Deaf and Blind. We decided to ask the Deaf Community which state deaf school was the second best in the country. We packed our bags and moved to Indiana during her 5th grade year. The Indiana School for the Deaf had already set up a Bilingual-Bicultural Program. It was fantastic! The children learned academics through American Sign Language and learned English in its written form. Speech training was available for those who wanted it. The best educational

situation of all.

Getting back to the USDB deaf classrooms—

In my youngest deaf child's classroom, the teachers were speaking and signing SEE sign. This was totally inappropriate to speak and sign at the same time. It interfered with learning. Steve Noyce, the USDB program director in control of my child's program, said he needed studies and research to prove ASL could teach the deaf student English.

I provided him with mountains of research. He said he had three huge file folders full of materials from me. Here I have ten pages of the articles I provided him. These can be shared with you, if you'd like have a look. (attached at the end)

Legitimizing ASL has been a long time in coming.

It was during the 1980's that ASL was accepted on the list of federally recognized Bilingual languages.

ASL was accepted as a bridge to communication with hearing children who had speech delays.

It also gained acceptance in high schools and colleges in meeting the foreign language requirement....and still the deaf student was denied this visual language.

More doors opened as studies were done on Learning English as a Second-Language and learning English in a Bilingual environment at home and school. This generally meant two spoken languages in the home. It wasn't long before these same Bilingual principles were shown to apply to ASL.

Educational research have shown that a child with hearing loss who knows ASL as their first language are more successful in learning English.

Deaf individuals also began getting involved in political and educational decision-making and insisting that ASL be included in the state deaf schools.

Here in Utah there is still educational time wasted as parents are erroneously routed through the Listening and Spoken Language program at the state school for the deaf. Those who advocate this LSL program think speaking and listening skills will be lost if a child who has hearing loss is taught sign while young.

I am here to tell you signing does not stop the acquisition of speaking and listening skills. I repeat, signing does not stop children with hearing loss from learning how to speak and listen. Signing actually helped my children know how to pronounce the words they could not hear !

The visual aspect of ASL fits the condition of deafness perfectly. It matches the visual nature of the child with hearing loss. It doesn't put undue burden on ears that can't hear perfectly. Rather it relies on the eyes that can see and comprehend communication.

There is no reason why children with hearing loss can not be ready for Kindergarten. Here is a list of 15 skills every child should know before entering kindergarten (attached at the end). Children with hearing loss can do what hearing children can do but they need language to do it !

Nowadays parents are very competitive to enroll their children into Language Immersion Programs in school districts. What a perfect Immersion program these parents of children with hearing loss have available. Their hearing children can also learn sign language which could become a job for them later as happened in our family.

The Deaf Mentor Program is another program available in Utah to families with 0-5 year old children with hearing loss. This provides guidance for the family in signing the language correctly and answering questions about Deaf Culture and expectations for children with hearing loss.

Due to current misinformation, many parents don't ask to get their babies into the Deaf Mentor program. This is really sad to me. Language delays occur because the child is not getting all the linguistic input they need while 0-5 years old. The child with hearing loss falls behind academically and socially.

It is wrong to deprive these children of language. Let me repeat, it is WRONG to withhold language from these children so that they are not ready for school. Too much emphasis has been on 'fixing' the deafness--when it's really a denial of and discrimination towards their physical condition.

There is a political movement abroad to ensure language access for deaf and hard-of-hearing children. This is a good movement. This movement is called Language Equality and Access for Deaf Kids (LEAD-K). Its goal is to ensure that children with a hearing loss are kindergarten ready by age 5.

With some help from Dr. Freeman King, Director of the Deaf Education Dept at USU and the Internet, I've got language-acquisition comparisons for you.

A typical Deaf child at
1 ½ years old knows-2 words
2 years old-12 words
3 years old-38 words
4 years old-48 words

A typical Hearing child at
1 ½ years old knows-10 words
2 years old knows-130 words
3 years old knows-208 words
4 years old knows-242 words

I say 'typical deaf child' because these studies were done on deaf children who did not sign. Dr. King said that deaf children whose parents used ASL could equal or

surpass these same milestones for hearing children.

Our challenge today is to reverse the misinformation that is out there about ASL and Education. Medical people need the truth because they give advice to parents. Parents need information that helps them understand the importance of giving their children language from infancy.

There is tremendous pressure placed on parents to follow the medical approach to deafness. It begins soon after the baby is identified with a hearing loss. The doctor or audiologist tell many parents the next step is a Cochlear Implant. Believe it or not, a Cochlear Implant is still a hearing aide and doesn't fix the hearing loss.

All of my three children who have hearing loss use hearing aides, sign, and speak. And why not ? Why not have access to all three of these modes of communication ? Of course signing provides almost fool-proof communication because it doesn't depend on their faulty hearing.

When I was raising my children who had hearing loss, many components of a successful education were not available to us in Utah. Now we have an excellent ASL/English School for the Deaf right here in Salt Lake City called Jean Massieu School for the Deaf. It was co-founded by Minnie Mae as a charter school and then came under the umbrella of the Utah Schools for the Deaf and Blind. It is an excellent school. My youngest deaf daughter graduated from the Deaf Education program at USU and became a teacher there. Part of her job was to evaluate children who came from the Listening and Spoken Language program. These children were not progressing in academic learning in the LSL program and were sent to the Signing program. With the access to language through ASL, these children gained 1-3 years of academic learning in one year. The success rate was remarkable. Language is the key.

At JMS American Sign Language is the language of instruction and English is learned in its written form. Speech training is also available for those who want it. This school has everything !

We can understand how the medical view became dominate in deaf education because of the training medical people receive. They are the mechanics for the body. They want to fix things. However, with increased knowledge about the social and cultural aspects of deafness, it is no longer seen as a medical problem to be fixed. Deafness is a culture and a society to be honored and placed at the highest priority of acceptance.

Language is a basic human need and applies to every child everywhere. What many people don't realize is how language has been denied many, many children with hearing loss. It is this language deprivation that we need to address and change into Language Equality and Access. Parents need to be told that their children with hearing loss need language and what that language looks like.

This is why this meeting is so important. I applaud your interest in seeing the deaf in a cultural way with a language of their own. This is healthy. This is the face of the

future. As medical people, you can share this cultural view with confused parents and help them accept their children for who they are.

Children with hearing loss are like foreigners. They can learn English through Second-Language learning strategies. Their hearing parents and siblings can adjust and create a language-rich environment for them as the family embraces American Sign Language. These families are not alone. American Sign Language is not impossible to learn. There are people to help.

I've tried both avenues. If I can save parents from wasting the time I wasted, I'd like to recommend each family with a family member with hearing loss start out with Sign Language. It was worth the time and effort our family put into learning sign language. Our children received a real education. Parents need you to tell them that. I hope you will consider what you can do to help educate parents in this important breakthrough regarding language, deafness, and education.

I know this has been a lot to absorb and understand. Thank you for your time and attention.

Bronwyn O'Hara