

# Deaf-Blind Perspectives

Volume 8, Issue 1

Fall 2000

## A Group for Students with Usher Syndrome in South Louisiana

Faye Melancon

**T**o begin with, Usher syndrome among the Acadian French people in south Louisiana was something people knew the “about” of, but not the “what” or “why” of. They knew that generation after generation of children were struck mysteriously with deafness and eventually with partial-to-full blindness. It was something that was dreaded, but had to be endured. Again and again, cousins, aunts, uncles, and sometimes two or three children in a family were found to have the condition, but no one knew what to do, or what to call it.

The “what” and “why” of it was that the Acadian parishes of south Louisiana have a far higher percentage of Usher syndrome than anywhere else in the United States. This extraordinarily high percentage has been documented in several studies (English, 1978; Kloepper, Laguaite, & McLaurin, 1966; Smith et al., 1992; Walters, Quintero, & Perrigin, 1982:). For example, Kloepper et al estimated that 30 percent of the deaf population in the parishes of Lafayette, Vermillion, and Acadia had Usher syndrome. This high incidence is a result of several hundred years of intermarriage among this close-knit ethnic group. Inevitably two individuals, both carrying a recessive gene for Usher syndrome transmitted to them by a common ancestor, marry and have children with this condition.

The Acadians, or Cajuns, as they are called, were originally from Acadia (Nova Scotia) in Canada. In the 1700s they were expelled from that area by the English. They moved down along the east coast of America, finally settling along the bayous of several south Louisiana parishes. At first they were not readily accepted by people in the area and were somewhat isolated both by language and culture. With time, however, the Cajuns came into their own and have won admirers around the world for their music, love of fun, and never-to-be-forgotten cuisine.

Many students at the Louisiana School for the Deaf (LSD) come from the Acadian parishes resulting in a high incidence of Usher syndrome at the school. According to Joyce Russo, project director of the Louisiana Services to Children and Youth with Deafblindness at the Louisiana Department of Education, these parishes include Acadia, Vermillion, Lafayette, St. Martin, Iberia, St. Mary, East Baton Rouge, Livingston, Ascension, and Orleans. Fifteen to twenty percent of children on the Louisiana deaf-blind census for children birth through age 21 are known to have Usher syndrome (Usher 1) as compared to an average of 3 percent for all other states in the nation.

When I became the counselor at the Louisiana School for the Deaf in 1974, I had no idea what Usher syndrome was. I wasn't aware that there was such a problem anywhere, much less at our school. I was a new counselor from the northern part of the state where there were no reported cases of Usher syndrome.

As time went on, students would offhandedly point out other students to me and hold both hands on either side of the face to describe them. It reminded me of how blinders on a horse would look. When I asked, “What do you mean?” they would answer, “You know, can't see on the sides.”

At first I was confused and thought the students were wrong, but I found myself watching the ones they had

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pointed out. I decided to bring them into my office and do some informal testing, such as standing off to one side and waving my hands. It gave me goosebumps when I realized, "Yes! Those kids were right!"

One of the good things about working at a school for the deaf is that networking and sharing knowledge is the norm. As I looked around, unsure of what to do, several people came to my aid. First and foremost, I was steered in the right direction by the principal at that time, Jerry Stewart, who had originally been at the Florida School for the Deaf and Blind (FSDB). Because some of the Acadian people had drifted down the east coast to Florida when the British evicted them from Nova Scotia, there were deaf students at FSDB who had Usher syndrome.

Next, I got in touch with Steve Barrett, who was the regional representative for the South Central Region of the Helen Keller National Center. The ball started rolling then. Steve was very helpful, flying over from Dallas several times in the fall of 1976 to help assess the situation. It was apparent that a schoolwide visual screening program was needed.

Because interest was picking up around the country regarding the probability of a high incidence of Usher syndrome in Louisiana, we were able to get the University of Houston College of Optometry, headed by Dr. James Walters, to come and test our students over the next several years.

After this, things started happening. New programs were suggested and genetic counselors came from as far away as New York. We got our own social worker especially for deaf-blind students, workshops were conducted to teach parents and children about Usher syndrome, and I started a student group called "The Lucky 10" in 1978. The name came from "lucky to get out of class." It consisted of tenth, eleventh, and twelfth graders who had Usher syndrome. By 1981, there were 17 in the group.

The goals of the group included independent living skills development, learning about resources available for people with limited vision, proper eye care, understanding laws and civic responsibility, decision making, consequences of actions, money management, development of self-worth, and communication skills. We met every two weeks.

Every Usher syndrome student group since that time has focused on a combination of fun and seriousness. We have gone on picnics, swum at nearby recreation parks, and taken field trips to Lake Ponchartrain for the wild rides, the IMAX in New Orleans, and the Observatory at Louisiana State University. We've skated, bowled, had cakewalks, exchanged gifts at Christmas, eaten at every restaurant in town (almost), and had barbecues and crawfish boils at my house. We saw the movie *The Touch* about a man with Usher syndrome who was struggling to assert his independence, every year until it went out of print.

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The students planned the activities, took care of the paperwork needed to get permission for activities from the school and parents, arranged for transportation, planned meals through the cafeteria, and took care of other necessary arrangements. They gained good management and organizational skills from these experiences.

An orientation and mobility trainer became a part of our group and went with us on outings and activities. The students were not required to have O&M training, but it became natural to participate because the trainer took them to Louisiana State University to practice and then followed up with food at a nearby restaurant.

More serious activities included learning about career centers and schools for deaf-blind people. We also produced and participated in a number of workshops. The students were responsible for the workshops. They wrote letters, designed programs, led groups, and, in short, ran the show.

One recent workshop called "Walk in My Shoes," featured Sister Bernadette Wynne, from the Technical Assistance Center at Helen Keller National Center in Sands Point, New York. The purpose was to raise the awareness level of other students at the Louisiana School for the Deaf, in order to help them better understand Usher syndrome, and stop the occasional teasing and bullying of students who had Usher syndrome.

Another recent workshop, "Open Your Eyes and See Us!" featured Dr. Bronya Keats from the Department of Biometry and Genetics at the Louisiana State University Medical Center in New Orleans. It focused on the students' feelings that others don't understand the nature of Usher syndrome and what people with Usher syndrome have to endure. Harry Anderson, who has Usher syndrome and is a guidance counselor at the Florida School for the Deaf and Blind, guided us through an Usher syndrome simulation experience. Each of the participants including students, parents and LSD staff wore ear plugs and eye covers that simulated sight with increasingly smaller and smaller degrees of central vision, culminating in no vision at all. Consciousness raising was immediate. We all expressed feelings of extreme frustration, fear, awkwardness, and sadness. The most significant result of the workshops was the empathy and respect that others developed for those who had Usher syndrome.

Another fun activity that we did for several years was to communicate with another Usher syndrome student group in Sweden. The students became pen pals. They exchanged letters, e-mail, pictures, and brochures. Each side bragged about its own country.

Each group invited the other to come and visit, and in fall of 1999, the Swedish group came to Louisiana. They stayed at the school for a week, and what a week it was! There were 14 visitors, 9 students and 5 adults. We showed them a Cajun good time. We hope to visit them in the future and several students are working on projects to raise money, including a website explaining the project and asking for donations.

The name of the student group changed twice through the years. In 1992, the group changed to "The Dice 12" because they said they had Usher because of the luck of the draw. In 1999, the group changed names again to "The Bravehearts," partly because of the movie that was currently showing in theaters and partly because they felt they had brave hearts.

The student group has filled an important need at the Louisiana School for the Deaf in this area of the country where there is such a high incidence of Usher syndrome. Over the years, the group has provided a wonderful opportunity for students develop skills, share experiences and support, and learn planning and organizational skills. The students worked hard to make this happen. They also provided an important service by educating others in the community about Usher syndrome and issues faced by people who have Usher syndrome.



*Faye Melancon recently retired from the Louisiana School for the Deaf after 27 years. She is currently taking an extended trip across the United States.*

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## Note from the Editors

In this issue of *Deaf-Blind Perspectives* we are pleased to publish both a poem and a short story in addition to a number of other articles. We would like to extend our thanks to all of the writers who have contributed articles for this and past issues. We would also like to encourage others to submit articles for possible publication in the future. *Deaf-Blind Perspectives* is a forum for everyone to share their thoughts, feelings, and expertise. We welcome submissions of a variety of types including professional articles, reports, practical tips, essays, poems, stories, announcements, and letters. If you have an article or other item that you would like to submit, or if you have questions or comments, please contact:

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*The following story was written by Deanna Baxter about her sister Emily. Emily was born deaf-blind. The story describes a trip that their family took from their home in Kansas to Maryland, where Emily received some medical tests. It describes Emily's everyday life, how people treat her, and how she deals with her lifestyle. The story was written 2 years ago when Deanna was 12 and Emily was 10. Emily has some vision and hearing. She wears glasses and hearing aids. Depending on the situation, she may use either sign language or speech to communicate.*

## Simply Emily

Deanna Baxter

**“H**ello,” said the doctor. I will be Emily’s doctor for the week. We are going to start by taking a sample of Emily’s blood.”

“Emily, this man is going to take some of your blood,” said her mother.

“If you will step this way please.”

Emily walked clenching her mother’s arm. She was very frightened. Emily may be deaf, but she still has a brain.

Emily was born deaf-blind. Which is not in any way bad. Like they say, “Everyone is different in their own little way.” She is just like anyone else; she can

recognize a place if she has been there before. Or, like if there is a place you go quite often. Emily has been to many places like this. She is so terrified of hospitals, because so many things have been done to her in the past at these places.

“Ok, here we go, we are going to take your blood now,” said the doctor.

Emily’s mother says. “You’re going to need a couple of other doctors to hold her down. Trust me she is very strong, when it comes to someone doing something to her that she doesn’t like.” Right about now Emily is screaming and kicking and trying to get loose. She cannot stand people holding her down, but there is no other way to get her blood taken.

She isn’t a very big kid either. She is 10 years old and only weighs 59 pounds, but when it comes to people messing with her, and she doesn’t want them to at the moment, she becomes very powerful.

“Just a few more minutes, you’re doing great Emily,” said her mother trying to comfort her.

Emily cries, “I want Deanna.”

“I’m right here, Emmy. Hang in there,” said Emily’s big sister Deanna.



**L to R - Emily, Deanna, and their sister, Jessie (standing).**

“Yes, you did it. Great job, Emily,” remarked the doctor.

Emily is not very happy at the moment, but in a few minutes she cools off, and she is ready to continue her day in a good mood.

“Emily, come on let’s go and get you some ice cream. You were so good,” Deanna told Emily.

The next day Emily had to go back and they performed some other kind of test on her. She contin-

ued to go to the doctor for awhile. Just like any other kid, she hated it with a passion.

On the plane on the way home, Emily and her mother were sitting by a young lady and her little girl who was 9 years old. She was so cute. Her name was Rachel. She really wanted to know a lot about Emily and what was wrong with her. She was interested to learn and try different things with her. She thought it was cool when Emily's mother was signing to her. Rachel told Emily's mother that she would love to learn how to sign. So Emily's mother showed Rachel how to do some simple signs.

Later during the flight, Emily and Rachel were asleep on each other's shoulders. They had become very close friends. Their mothers had been talking a lot about the two girls. Emily's mom told Rachel's mom that Emily didn't have very many friends. She said that people just don't know what to say. All they know how to do is stare. Rachel's mother agreed. "They treat my daughter the exact same way, but the only difference is that Rachel is a different color than them. She doesn't really understand why very many people don't like her. I have tried and tried to explain. It just doesn't work. I don't know if she is just too young to understand or if she doesn't want to try to understand."

A voice over the intercom interrupted them, "Please stay seated until the plane is landed. Thank you for riding with us. I hope you enjoyed your flight."

The two families said their good-byes and said that they would keep in touch so that the girls could get to know each other a little more.

"Hey, would you and Rachel like to come down and go to the fair with my family this year?" asked Emily's mother.

"Sure, that would be so much fun!"

The two families parted and they thought about each other constantly. They kept in touch and visited each other a lot. Let this be a good lesson to people who think that just because people look different, it doesn't mean that they're a bad person. So, just as the golden rule still reads, "Do unto others as you would like them to do unto you."



## Miss(ed) Communication

Lisa Kozlik

*Everyday, strangers pass me by  
without saying a word.  
They use their voices to speak OF me,  
- but don't take the time to speak WITH me.  
I wonder why.*

*As I walk along the sidewalk, one person says  
to another, "Look at her."  
- they are pointing at me.  
Suddenly, the voice disappears.  
Where did it go?  
I don't know.*

*While I'm in the mall shopping with friends  
another voice says, "Look at her."  
- they are talking about me.  
But who spoke those words?  
I never found out.*

*What I cannot see and hear,  
I experience through touch.  
Why isn't this good enough  
for those of you who pass me by?*

*Sign language is my communication with the  
world,  
- just like the voices you use to speak of me.  
Braille is my "information highway" to the  
world,  
- just like the fingers you use to point at me.*

*The next time you see me,  
please  
just don't look at me  
- get to know me.*

### About the Author

My name is Lisa Kozlik. I am a 29-year old college student from Wisconsin. I am also deaf-blind. I have light perception and a severe hearing loss. My blindness and hearing impairment were caused by premature birth complications. I have been a dog guide user for the past 8 years. My current guide is a three-year old yellow lab from Leader Dogs. Five years ago, I sought training at the Center for Deaf-Blind Persons in Milwaukee, Wisconsin. Their help and support have given me the strength to believe in myself and to share this poem with you, the readers of *Deaf-Blind Perspectives*.



## Intervener Update

Peggy Malloy, DB-LINK  
Betsy Bixler, NTAC

**T**he role of interveners in the education of deaf-blind children is receiving more and more attention these days. In February 2000 in San Diego, a group of individuals interested in exploring this topic met to discuss issues pertaining to the use of interveners—what intervention is, what the role of interveners is, and how they should be trained and supported.

The meeting was sponsored by Helen Keller National Center (HKNC) and facilitated by Joe McNulty, Director of HKNC. Present at the meeting were several individuals with expertise on the topic of intervention, parents of deaf-blind children, and representatives from HKNC, DB-LINK, NTAC, NFADB, and several state deaf-blind projects. The meeting focused primarily on the use of interveners in early intervention and educational settings.

At the meeting, the status of interveners in both the United States and Canada was discussed. Much of the discussion about what is happening in the United States focused on a review of a briefing paper about interveners written by Linda Alsop, Robbie Blaha, and Eric Kloos (2000) and recently published by NTAC. The paper provided an excellent basis for discussing the various issues of interest to the group. An overview of the Canadian system was provided by Linda Mamer.

This article summarizes some of the main points of the briefing paper. The paper itself goes into greater detail about each of these points as well as other relevant issues. A description of intervener services in Canada follows the briefing paper summary.

### Briefing Paper Summary

#### What is an intervener?

An intervener is a person with special training in deaf-blindness who works one-to-one on an ongoing basis with a child or young person who is deaf-blind. The intervener is a consistent presence in the child's life and helps the child gain access to the world. Intervenors do not work in isolation, but are members of Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) teams. In school settings they work under the direction of the classroom teacher. In early intervention settings they may be supervised by an early intervention specialist or other service provider.

#### What is the role of the intervener?

Intervention is a process that provides access to visual and auditory information for a deaf-blind child. The role of the intervener is to facilitate that process. Deaf-blind children have unique needs that can be addressed by the process of intervention. These include

- ◆ Access to environmental information
- ◆ Communication
- ◆ Social and emotional well-being

Intervenors provide clear and consistent *access to environmental information* by using strategies tailored to each child's unique capabilities to help them access information that is usually obtained through hearing and vision, but is unavailable or incomplete to deaf-blind children. They facilitate *communication* by being consistently available to the child to promote the development and use of communication skills. They serve as a link to help the child communicate with others. Intervenors develop a trusting, interactive relationship with the child that promotes *social and emotional well-being*. This relationship can help motivate the child to be in contact with the world outside his or her own body.

Intervenors also have additional responsibilities as determined by the goals of the IFSP or IEP. These include supporting the child during daily routines and activities and vary depending on the needs of the child. For example, an intervener working with an infant in the home may be involved in activities such as dressing and play. Responsibilities of an intervener working with an elementary school child may involve academic work and social activities. An intervener working with a high school-aged child may be involved in job coaching. During these times of additional responsibilities, however, the intervener's focus continues to be on promoting the process of intervention by meeting the child's needs of access to environmental information, communication, and social and emotional well-being.

#### Does the deaf-blind child become dependent on the intervener?

Rather than create dependency, the intervener promotes the child's independence by facilitating access to information, providing opportunities that allow the child to solve problems, make his or her own decisions and choices, and interact fully with other people. The intervener acts as a bridge, not a barrier.

### What type of training and skills do interveners need?

Training for interveners should occur at two levels. The first is training that provides basic information about deaf-blindness including characteristics of vision and hearing loss, communication, concept development, and learning. The second level is training tailored to the specific needs of individual children. Child-specific training varies depending upon characteristics of the child, including age, severity of vision and hearing loss, presence of other disabilities, communication needs, and the setting (e.g., home, school, or community) in which the intervener's services are provided. Because interveners work as part of a team to develop and provide services for deaf-blind children, they should also receive training that will help them acquire teaming and collaboration skills.

### How do you know if a child needs an intervener?

The need for an intervener for a particular child is always determined by the IFSP or IEP process. This follows a thorough evaluation of the child's strengths and needs. An intervener is not automatically provided for a child or student who is deaf-blind, but should be a valid option on a menu of services available to support the implementation of the specially designed instruction of the child's IFSP or IEP.

### Is the word "intervener" spelled with an "er" or an "or"?

The term intervener originated in Canada where the "or" ending is used. The authors of this briefing paper use the same term, but with an "er" ending. This was an outgrowth of practices in Utah where administrators and service providers officially adopted the spelling as intervener.

### Intervenor Services in Canada

At the meeting in San Diego, Linda Mamer described intervenor services for students who are deaf-blind. In Canada, intervention for people who are deaf-blind has been a service delivery model for more than 25 years. The Canadian Deafblind and Rubella Association (CDBRA) believes that every person identified as deaf-blind has the right to receive lifelong intervention services (Mamer & Munroe, 1999). The term "deaf-blind" as used by CDBRA refers to individuals with congenital or early-acquired deaf-blindness as this is the main area of their experience and expertise. McInnes (1999) defines intervention as a process that enables "the deafblind person to establish and maintain

maximum control over his or her environment at a level appropriate to physical ability and level of functioning" (p. 76).

The Canadian Deafblind and Rubella Association has developed a working paper of national guidelines for intervenors. The guidelines promote intervention as an appropriate and viable model for deaf-blind individuals. CDRBA recognizes the significant impact that an intervener can have on an individual's learning and experience and emphasizes that an intervener enables the individual to access information, communicate, and fully participate in making choices (Mamer & Munroe, 1999). The intervener should facilitate the deaf-blind individual's needs and desires.

School intervener services are individualized and available for deaf-blind students throughout the educational years in many parts of Canada. In some areas, intervention services are also available after-school, weekends, and summers.

### Future Activities

Crucial needs identified by participants at the meeting in San Diego included development of a list of competencies for interveners and formalized training opportunities on a national level. A subgroup of the participants plans to pursue these objectives in the future. Another subgroup is developing a values/mission statement on the need for intervention services for deaf-blind children and youth. Participants at the meeting also identified a need for more widespread information about interveners and hope to promote awareness through publications like *Deaf-Blind Perspectives*.

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*Attendees at the San Diego Meeting*

Joe McNulty - Director, Helen Keller National Center

Linda Alsop - SKI\*HI Institute, Utah State University

Betsy Bixler - Area Director, NTAC, Helen Keller National Center

Robbie Blaha - Education Specialist, Texas Deaf-Blind Project, Texas School for the Blind and Visually Impaired

Cathy Kirscher - Regional Representative, HKNC Southwestern Regional Office

Eric Kloos - Project Director, Minnesota Deafblind Project

Peggy Malloy - Information Specialist, DB-LINK

Linda Mamer - President, Canadian Deafblind and Rubella Association

Carrie Masten - Parent; Family Support Partner, Washington State Services for Children with Deaf-Blindness; Representative, National Family Association for Deafblind

Loretta McGraw - Project Director, Connections Beyond Sight and Sound

Pearl Veasart - Parent



## AADB Convention 2000

Roma Vanduzer,  
Chairperson, Arizona Association of the  
Deafblind of Tucson

**T**he American Association of the Deaf-Blind convention held in Columbus, Ohio this year from July 29th to August 4th was, in my opinion, a tremendous success. Considering that more than 1000 people attended, things went along relatively smoothly. There were numerous well-presented, educational workshops. Many provided Braille handouts. There were also many enjoyable tours. So many activities were offered that it was difficult to choose among them. The only problem, from my personal viewpoint, was that most of the places selected for tours were so filled with fun things to do and see that I could have spent a whole week in each place!!

There were two big parties. The first, on Sunday, July 30th, was a celebration of the 25th anniversary

of the first AADB convention held in 1975. The theme of the second party, on Wednesday evening, August 2nd, was "Let's Swing into the 21st Century." Large crowds attended both parties. Everyone danced exuberantly, ate and talked, and made new friends.

On Sunday, there was an opening ceremony in the afternoon. All who attended enthusiastically cheered the roll call of the states. Wednesday was entirely given over to business meetings. The new AADB bylaws were reviewed, discussed, and put to a vote. Late in the afternoon they were unanimously accepted. Considering that a large number of people attended the convention, I was surprised and disappointed that there were not more people at the meetings. Exhibits and crafts displays, however, were held at the same time. There was a great deal to see, including interesting product displays, beautiful crafts, and souvenirs like t-shirts. Despite all of the excitement, business was very competently taken care of and concluded, and that's what is important.

Overall, it was a great convention. The housing was comfortable, private, and very clean. The food was delicious and the transportation conveniently available at all times. Shuttle buses conveyed people to and from points of interest and other places they needed to go.

It is important to keep in mind that one of the major reasons for the success of the convention was the large number of volunteers (support service providers) who gave a whole week of their time, skills, and services with selfless dedication to assist us with anything at all when we needed help. We extend our heartfelt thanks to all of them!!

The banquet on the last evening was great. The food was excellent and expertly catered. Many awards were given and many people were recognized for their services to AADB. President Harry Anderson was his usual cheerful and amusing self.

On Friday, August 4th, transportation to the airport was well organized and efficient. Hey, no one in our group even lost any luggage!!



The following article is reprinted with permission from the March 2000 issue of *VIEWS*, a monthly publication of the Registry of Interpreters for the Deaf.

## Team Structure for a Deaf-blind Student

Betsy J. Dunn, CSC, California

**T**he successful educational experience of a student who is deaf-blind is always the result of a team effort. It would be impossible for any parent, teacher, support staff or administrator to single-handedly ensure the educational/social success of a student requiring extensive support. The complex and multi-layered educational and social needs, preferences and styles of a deaf-blind student mandate a sophisticated network of support that can only be provided by a team of professional individuals who listen carefully and respond appropriately to the deaf-blind student.

The individual needs of a deaf-blind student are as varied as each student, and yet, the structure of the support team needed by this widely varying group is very similar. A successful support team for a deaf-blind student includes the following individuals:

- ◆ Student
- ◆ Parent
- ◆ Administrator/Case Manager
- ◆ Primary Support Teacher
- ◆ Interpreters
- ◆ Vision Teacher
- ◆ Mobility Instructor

Team success requires that each team member have a clear understanding of their own role, the role of other team members, and how each member interacts and supports the other. Team members must actively share information and seek assistance from others. Equally important, they must be willing and able to put the needs of the student ahead of any personal issues or agendas. On-going team success requires constant communication, respect and competency in each and every role.

### Role Definitions

The first and most important member of the team is the **student**. The student's individual needs, preferences, and styles as they relate to communication and education must be addressed and accommodated by the support team's efforts. Individual pro-

files of interest, potential and skills provide necessary direction for the student's educational goals. As the student matures and is able to participate in his or her own IEP with increasing awareness and responsibility, the success of the support team will be reflected in the educational ownership and self-awareness of the student.

The **parent** is the driving force of his/her child's educational experience. Without strong advocacy from the parent, it is too easy for a deaf-blind student to be under-served or not served at all. The parent provides essential input and direction in the IEP. Some educators might prefer the parent simply rubber stamp decisions made by school personnel. This, however, is not the most effective relationship for student success. The parent is able to bring a wealth of background information to school personnel – and through this information, the school staff can better understand and guide the student to academic/social success. Even when a full ensemble of professionals has been brought together to provide educational support, the parent still continues to be a vital team member. The need for parent input and direction is never-ending.

The **administrator or case manager** acts as the school site coordinator for the services and personnel providing support to the deaf-blind student. From the student's perspective, the administrator/case manager may seem like a "silent partner" on the team. Although the case manager may not be the most visible team member, experience has proven that the case manager's support, guidance and administrative skills interfacing with the school district is a vital element necessary for the team's success. A good administrator can listen and learn about the issues of deaf-blindness and effectively oversee and coordinate these services.

The support team "**teacher**" may be called many different names: primary teacher, primary support teacher, teacher of the deaf, point person, or special education teacher. Whatever the name, this "teacher" is a pivotal team member who not only provides 1:1 teaching and tutoring, but also interfaces and coordinates with the general education teachers, interpreters, parents, and administration. Additionally, the primary support teacher must modify, adapt, and create materials necessary for the student to participate, understand and master the information presented in the general education and during 1:1 instruction periods. The teacher must work closely with the student and parent to ensure that the educational direction and needs of the student are represented in the IEP document.

To the general school population, the **interpreter** provides the most visible support to the deaf-blind

student; it is also a complicated and often misunderstood position on the team. The school district employee title of “interpreter” is generally inadequate and does not represent the variety of duties required by this position. The interpreter’s daily responsibilities are a blur of interpreter, tutor, social facilitator, and Service Support Provider (SSP) duties.

Functioning as the “interpreter,” this team member facilitates and creates the information and communication bridge necessary for social opportunities and educational experiences to occur. Deaf-blind interpreting requires specific knowledge and skills beyond those necessary for sign language interpreting. The interpreter literally brings the world to the student and the interpreter’s ability to clearly and accurately convey visual and auditory information – as well as social nuances – will determine the level to which the student can rise. Sensitivity, awareness, and training in deaf-blind issues and needs are required for the interpreter to successfully support the deaf-blind student. The individual needs, desires, and preferences of the student must be respected and accepted during interpreting situations.

Educational interpreters sometimes find themselves in the dual job description of interpreter/tutor. This blurring of roles can be confusing not only to the student, but also to the interpreter and general education teacher. Clear definition and distinction are necessary for the successful blending of these roles.

While interpreting in a social setting, the interpreter for a deaf-blind student is called upon to “facilitate” social interaction with the general school population. This is an appropriate and necessary role to embrace, and yet it adds additional confusion of the interpreter’s roles and responsibilities. Continued professional development and growth are vital for the development of skills necessary to discern when and how to function as a facilitator while also maintaining respect and regard for the deaf-blind student’s social/emotional development and abilities.

In addition to functioning as interpreter, tutor, and social facilitator, the interpreter for a deaf-blind student also serves the student as a Service Support Provider (SSP). As an SSP, the interpreter will act as the deaf-blind student’s guide, lunch partner, or companion. The student’s personal needs or preferences for support will determine how and when the interpreter functions as an SSP.

Deaf-blind interpreters work under unusually close and intimate conditions with the deaf-blind student. This unusually close working relationship - as well as the intensity, which often accompanies it - is im-

portant to acknowledge and support. Too often, interpreters reach “burn-out” because these issues have not been anticipated, addressed, or supported. For this reason, it is preferable for the deaf-blind student to receive alternating services from at least 2 interpreters throughout the day.

The **Braille and Mobility Instructors** both provide specific training and expertise for the student and other team members. Their input regarding specific skills and strategies related to deaf-blindness are beneficial to all team members.

### Communication of Role Definitions

Various methods may be used to define, establish and communicate the role of each team member within the team as well as to the general educators or other persons who are part of the larger support network. The roles and responsibilities of team members may be introduced to the general education teachers through an orientation meeting, which takes place before the beginning of each school semester.

During an orientation meeting, or in a 1:1 setting, a one to two-page “fact” sheet can be utilized to provide information addressing these questions/topics:

- ◆ Who is the student? What does s/he like to do?
- ◆ Functional aspects of vision and hearing: How much can s/he see or hear?
- ◆ Types of educational materials used: does s/he read Braille or print or both?
- ◆ Communication options in the classroom: sign language through the interpreter, writing, or gestures/body language.
- ◆ Define the interpreter’s role, responsibilities, and duties: Visual and auditory information is relayed and tutoring assistance is provided as necessary. Classroom behavior management is the responsibility of the teacher.
- ◆ Identify special space/environmental considerations: What seating arrangement is appropriate? Use of the over-head projector and movies.
- ◆ Describe how the student will complete class assignments: describe the 1:1 study support s/he receives.
- ◆ Indicate who and how the student will be graded.
- ◆ Provide a list of the names and phone numbers of all team members.

Role-playing may also be successfully employed during a teacher orientation as a means to demon-

strate and clarify the role of the interpreter/tutor in the classroom setting.

Due to the fact that team members will naturally change over the years, and substitute teachers and interpreters will also require orientation information, a basic interpreting/teaching guide of practical information which addresses deaf-blind interpreting in general, and the individual student's needs specifically, should be disseminated to facilitate the smooth transition of new or substitute team members.

Topics addressed in the interpreter/instructor guidelines for a deaf-blind student may include:

- ◆ **Interpreter dress:** Clothing which contrasts the skin tone of the instructor/interpreter. If a particular color is preferred, this should be clearly stated.
- ◆ **Getting started:** What to do when first meeting with the deaf-blind student.
- ◆ **Sign Language:** Preferences of the student.
- ◆ **Lighting:** Optimal conditions and alternatives.
- ◆ **Interpreting:** Guidelines, techniques, and strategies for deaf-blind interpreting; defining the expanded deaf-blind interpreter's role as an "SSP" for the student; as well as identifying the language and communication preferences of the student.
- ◆ **Mobility:** Strategies, techniques, and student preferences.
- ◆ **Social Etiquette:** Student preferences/needs; general deaf-blind courtesies.

Technical support and assistance available through various national organizations, and schools serve as invaluable resources to the professional development and role definition of the student's support team. Team members should be encouraged and challenged to define, communicate, and nurture their professional skills so that they may better provide the support structure needed for student's success.

Some parents may dream of finding an "Anne Sullivan" for their deaf-blind child; a person who might magically bring the "world" to their child. However, the strength and knowledge of a team provides a more powerful and dynamic educational experience than any single parent or teacher could ever dream of giving an individual who is deaf-blind.

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## Meet the NTAC Staff

**N**TAC, the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind provides technical assistance to families and agencies throughout the United States. NTAC's mission is to provide assistance that enables people and agencies in each state to work together to improve the quality of early intervention and educational services provided to children and young adults who are deaf-blind. NTAC's ultimate goal is to assist states to improve outcomes for deaf-blind students to meet challenging standards and be better prepared for adult life. Technical assistance activities include setting up training opportunities for families and service providers, consultations, and facilitating collaboration among agencies and organizations within a state.

Technical assistance activities are planned through each state's deaf-blind project and are provided to agencies and organizations that provide services for children and youth who are deaf-blind (birth to 28 years). These include state deaf-blind projects, family or consumer organizations, and state education, early intervention, and adult service agencies.

NTAC combines the resources and expertise of two organizations, Teaching Research at Western Oregon University and the Helen Keller National Center (HKNC) in New York. NTAC is funded by a grant from the U.S. Department of Education to Teaching Research.

Staff are located in four regions. Each office provides technical assistance for the states in their region.

**Region 1** (AK, AZ, CA, CO, ID, HI, MT, NV, NM, OR, Pacific Basin, UT, WA, WY), Teaching Research, Monmouth, OR

**Region 2** (IA, IL, IN, KS, MI, MN, MO, NE, ND, SD, OH, WI), Shawnee, Mission, KS

**Region 3** (AL, AR, FL, GA, KY, LA, MS, NC, OK, Puerto Rico, SC, TN, TX, Virgin Islands), Atlanta, GA

**Region 4** (CT, DE, DC, MD, MA, ME, NH, NJ, NY, PA, RI, VA, VT, WV), HKNC, Sands Point, NY











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