

SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND
DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS
A collaborative effort of the Texas School for the Blind and Visually Impaired
and Texas Commission for the Blind

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Kate's Corner

So much for the notion of the lazy, hazy summer days with not much to do. As July draws to a close and we anticipate school beginning in several weeks, most of us here in Outreach are wondering where the time has flown. We must be having fun. In June we were involved with a workshop for parents and young children called "On the Move" and Texas Focus took place in El Paso. At the end of the month, I was fortunate to be able to attend back-to-back workshops in Minnesota sponsored by Hilton Perkins, NFADB, and NTAC focusing on Family Specialists and providing effective technical assistance to families. Summer Technology training begins next week, and work has begun towards developing new workshops and the Texas Symposium on Deafblindness. There are a variety of other projects cooking and some changes in staff to round out August.

One of the big changes has us dropping breadcrumbs from Outreach to the new office of Debra Sewell, Education Specialist with VI Outreach. After seven years in Outreach she is moving her office to the Curriculum Department. We won't say goodbye because we refuse to let her go. Debra is replacing the fabulous Nancy Levack, Curriculum Director, who is leaving for Utopia (Texas that is). Also departing Curriculum this year is Brigitte Starkey who will devote her full energies to her own company. We appreciate all the fine work they have done in developing educational materials for the families and professionals involved with visually impaired children.

Speaking of those materials, one of the products from our Curriculum Department is the book *Teaching Students with Visual and Multiple Disabilities: A Resource Guide* written by Millie Smith (formerly with Outreach) and Nancy Levack. Millie and Nancy were recently awarded the C. Warren Bledsoe Award at AER International for this publication. We are very proud of their accomplishment and want to extend our heartiest congratulations.

Another award, the Mary K. Bauman award, was given at AER International this year to our very own Dr. Phil Hatlen, Superintendent of TSBVI. It is given to an individual who has made a significant contribution to the education of children who are blind and visually impaired. How suiting that this award was given to a person such as Phil who, in the words of Dennis Thurman, is "a teacher in the deepest, noblest sense of that title . . . a teacher with only the betterment of children in mind."

Rita Livingston, Principal of Comprehensive Programs, has made the decision to leave TSBVI. We wish her the best with her new endeavors. Miles Fain will be taking over as Rita departs. Many of you know Miles as both a teacher and assistant principal here at TSBVI. Dr. Lauren Newton will continue as Principal of Special Programs. Be sure to read her article on page 38 that describes some of the exciting new short programs available to students with visual impairments who are attending school in their local independent school districts. Other

changes for the coming year include a new program structure for the Comprehensive Programs, expanded distance education efforts, and the continued remodelling of the TSBVI facility.

Last but not least, we want to welcome Ann Adkins to Outreach. Ann will be taking the Outreach position vacated by Debra Sewell. Ann has recently been a teacher of the visually impaired in the Eanes ISD, but has a long history as both a regular and special educator. We know she has much to offer the children of Texas in her new role with Outreach and look forward to working with her.

Editor’s note: You can’t work in the field of special education and disability very long without experiencing the death of a child. Not everyone is comfortable talking about it – but it happens, with and without warning. Families with chronically ill children face this possibility daily. We all experience loss in our lives whether it is a marriage ending, a child graduating, a job ending, or a relative dying. Even if the change is good, letting go of your old identity with its roles and responsibilities is a process that takes time. My parents are still living, but I wonder, will I no longer feel like a daughter when they die? As Dr. Ken Moses says, “There is no right or wrong with feelings, they are just there.” One way of living through the grief process is writing about it. The following articles written by two moms and a grandmother reveal their varied reactions to the loss of a child. All three are insightful and comforting. We hope their words will help you better understand their grief and also their joy in sharing the beautiful though brief lives of these children.

Ben’s Eulogy
By Alison Rickerl, Mom, Houston, TX

No more oxygen tanks, pulse oxymeters, and vile medications. No more standers and wheelchairs and AFOs. No more nebulizer treatments and cleaning vomit off the carpet. No more late night emergencies, hospitalizations, tubes, wires, and syringes. Blessed relief... No more hug and kisses. No more crooked smiles. No more delighted full-body wiggles. No more roughhousing on the floor. Wretched grief...

My son died. Some say there is no greater pain than to lose a child. I’m sure others feel that pain every bit as keenly as I do. Ben touched many people very deeply. That pain would not hurt so much if the love was not so deep. There is no greater love than that of a parent for a child.

Benjamin was only 3 years old when died. In three short years, Ben faced more medical problems than most people do in 75 years of life. His disabilities and health impairments have

hardly been conducive to a “normal” lifestyle. Life has been difficult for all of us these past three years – but I would not trade a second of it. Ben was an incredible gift of love, and I am so grateful for the time I had with him.

Many years ago, I prayed for patience. So God sent me Meglyn, my first-born, and I learned. But I was still dissatisfied with my ability to cope with such an energetic child. So I prayed for more patience. And God sent me Madison. Between the two of them, I learned how to be patient with all kinds of children. But still I didn’t think I was quite where I needed to be. So I prayed some more, and God sent me Ben. That’s when I learned how to be patient with adults, too.

Madison and Ben have both brought into my life such diversity and understanding of the bigger picture. From the moment, five years ago, when the doctor shook his head and said my daughter would never see, I knew life would never be the same. I was not allowed to stay the same, to become stagnant in my abilities and thinking. In advocating for my children’s needs in the education, social service, and medical systems, I grew in every way. Meeting their needs has done more than any other experience I’ve ever had to help me purge selfishness and pettiness from my heart. They have helped me develop a deeper understanding and compassion for all people. My children have molded me to be confident in my ability to tackle the various hurdles in those arenas. Ben, especially, gave me the courage to face my worst fears and still do the best job I could as a mother.

Ben has moved me to learn more, do more, and be a better person. Even though he was blind, he gave me eyes to see what I had not seen before. Even though he was deaf, he taught me to listen with an open heart and mind. Even though he was very sick, he gave me enormous strength. Ben gave me such joy. The smallest things gave me the most enormous pleasures. The brief moments that I could hold his hand, the rare time he was able to hug back, the times he was able to let me hold him for hours, and even roughhouse, the beautiful smiles, the stiff wiggle of his body when he was delighted . . . these moments were better than vacations, promotions, and fancy parties. With his needs for expensive health care and equipment, I knew I’d never drip with diamonds . . . better, I dripped with joy and happiness.

Because of Ben, I have known complete joy and happiness. I thank God everyday for sending him to me.

I believe that Ben has fulfilled his purpose here on Earth. Many of us spend decades trying to do what we are called to do – invent something, improve something, whatever. Some never do fulfill their calling. In just three short years, Ben has done more; through him, souls are saved. He has touched each of us deeply and we are forever changed.

To those of you who were afraid of his disability and health impairments, please let his life and death inspire you to reach out to others in need. If you are lonely, take heart that it is in

the giving of love to others that you learn to feel truly loved.

I know you feel very sad for me. But it is that feeling – that ability to truly feel caring and giving – that inspires the best in all of us. Don’t turn that off. Let that pain turn into the glow of joy and the ability to easily give to anyone in need at any time. In that way, my loss is not in vain, and Ben’s life and death will have helped so many people.

Aging, Loving, and Loss

By Brenda Placette, Grandmother, Houston, TX

My three-year-old grandson, Ben Rickerl, died last Tuesday night. For the last fourteen months of his short life, his only nutrition was Neocate, a special formula available by prescription only, which his parents administered to him through a bottle. Because of Ben’s severe allergic reactions to food, it was the only nourishment he could tolerate. In early 1999, an attempt to feed him goat’s milk, recommended by one of Ben’s doctors, resulted in anaphylactic shock and an extended stay at Texas Children’s Hospital in intensive care.

Ben was born with Joubert Syndrome, a very rare genetic disorder. His 7-year-old sister, Meglyn, is unaffected, but Madison, age 5, also suffers from the syndrome and is blind. Her speech and gait are affected by hypotonia, low muscle tone, but she is a happy child who is attending kindergarten. Joubert’s is characterized by multiple sensory and physical disabilities as well as health impairments.

In Ben, Joubert’s manifested itself in particularly insidious ways. Although classified as deafblind, he had some hearing and loved reggae music and the sound of his Daddy’s voice. He had many health problems resulting in numerous hospital stays. He had to have round-the-clock care to access the medications, nebulizers, and interventions to keep him alive.

Ben had started school two months ago, and loved the wheelchair lift on his special education bus. His teacher, Mrs. Cockrell, and his two aides reported progress, and his mom and dad noted excitedly that he was making new sounds.

By the time Ben was born, my daughter Alison was already immersed in the special world of the disability community. The Rickerl home was full of people constantly: orientation and mobility and vision teachers; occupational, physical, and speech therapist; people delivering and setting up durable medical equipment. Alison sought out all resources for Madison, joined many disability groups, and became a leader in some.

In March of 1997, the Texas Association of Education and Rehabilitation of the Blind

and Visually Impaired named Alison, Exceptional Parent of the Year. Their annual conference was held in El Paso, and I attended to help with Ben, since Alison was nursing. As I sat in the audience of 200 educators holding my precious grandson, Alison accepted the award and without notes thanked two-dozen people in the audience by name and talked about the importance of teamwork between parents and teachers to optimize educational outcomes. It was a bittersweet moment: I thought what an incredible person my daughter is becoming through the gifts of these special children.

When Ben died, Alison and Ted's first thoughts were how to help other parents who have children with Joubert's, and they donated Ben's brain, kidneys, and retinas - the organs most affected - to the Joubert Foundation.

One hundred and twenty-five people attended Ben's visitation and five-hundred attended his funeral mass. Shortly before the graveside service began, my 90-year-old great-great Aunt Peachie walked unsteadily down the long gravel road to the gravesite, aided by a walker. Her daughter, who is waging her own battle with pancreatic cancer, accompanied her. At the service, my daughter Alison eulogized her only son. She said she felt that Ben had served his purpose in life — something that takes many of us years to identify and fulfill. He had saved some souls and touched so many lives.

The disability community is a big, extended family. They share their pain, but they also share their joy. Grounded in realities that are sometimes incredibly harsh, they are very connected to each other emotionally. I am so grateful that I live in this world.

Growing older is always about loss. We all lose our parents. Our joints, muscles, and organs react differently. Our spouses and friends die; occasionally we lose a child or grandchild. It hurts; for a while we think we may not be able to endure the pain.

On the three-hour trip to Union Cemetery in Teague, Texas bright splashes of bluebonnets and Indian paintbrushes adorned the countryside. I thought, "Right now babies are being born, people are falling in love and getting married, people are celebrating their 50th anniversaries, and people are being buried." Life is glorious and it is also very painful. In the past week, I've witnessed what people refer to as the "triumph of the human spirit over adversity" many times. As the small white coffin was being closed for the last time, five-year-old Madison said, "Bye-bye Little Ben." All of us who knew him and loved him are better for that experience. Isn't that the ultimate measure of a life?

For more information about Joubert Syndrome, visit <www.joubertfoundation.com>.

Franky's First Steps

By Connie Vasquez, Mother, Longview, Texas

In the Spring 2000 issue of *SEE/HEAR* I wrote the story of our son Franky. In case you didn't get a chance to read it, here is a brief summary. Franky was born with microcephaly, calcifications of the brain, blindness, deafness, severe developmental delay, cerebral palsy, seizures . . . Over time he developed severe reflux. Not only that; his jaw was receded and his soft palate extended way into his throat, constricting his airway considerably. He had to be catheterized, suctioned, tube-fed, plus he took about eleven medications 2-4 times each day. We had been warned that he could die of pneumonia or apnea (stop breathing).

I was very saddened to read a few months back of the problems people have faced taking their disabled child to church. I know some people don't consider church a very important part of their lives. Still there are those of us who find our strength and comfort in church. To those of you who have encountered difficulties, I encourage you to keep looking. There are churches out there that care; I know from experience. We have lived in three different places since Franky was born in 1993 and belonged to three different churches. We have never encountered difficulties because of Franky's disabilities. In the first two churches, Franky was usually in the nursery. The ladies spoiled him rotten. When Franky was two years old we moved to Longview, Texas and joined the Longview Baptist Temple. We became part of the Spanish and the English church. The English church is very large with four nurseries and many Sunday school classes. The nursery superintendent told me I could put him wherever I wanted. As he grew older, we decided to put him in Sunday school to stimulate his development. Most recently he was in the three year old class. The teachers accepted him eagerly and encouraged the other kids to interact with him.

Eventually we put him in the regular church services. He was very noisy sometimes. His breathing sounded like a loud snore. When I asked the pastors what to do, they told me not to worry about it, everyone would get used to it. No one ever complained or asked us to take Franky out of a service; although I have chosen to do so on occasion, especially when he threw up!

When my daughter, Teresa, was born on a Saturday evening, it was the Spanish pastor's wife who took care of Franky, making sure he got his food and medication. When Teresa had emergency surgery on a Sunday at seven weeks of age, one nursery worker dedicated her whole time to make sure Franky got fed. Now we have family living nearby. As Franky became more difficult to care for we did not use the church people as much, but they were always there for us, praying and giving moral support. Their support, that always has meant so much, became a lifeline as Franky's health and quality of life rapidly began to decline.

When Franky was awake, the only way he could breathe without struggling was if we sat

him in front of us and pushed his jaw forward to open his airway. However, his left hip had become dislocated, so sitting for any length of time was very painful. He became very fussy, and we tried changing his medicines and dosages. It didn't help. It got to the point where the only time he was comfortable was when he was sleeping on his stomach. Unfortunately, his feeding tube had become enlarged and lying on his stomach caused it to leak. The surgeon experimented with different sizes of tubes; each would last about a week before it would start leaking. The entire contents of his stomach would leak out in just few minutes.

Franky was miserable, and it was only getting worse. As much as we loved him, we were beginning to realize it was time to let go. The pediatrician suggested a "do not resuscitate" order. After much advice, thought, and prayer we decided that was best for him, no drastic measures to revive him would be taken.

In three weeks time Franky got a kidney infection, pneumonia, a staph infection, and a fungal ear infection. He was deteriorating rapidly. He came down with a head cold, and I took him to the doctor just to be on the safe side. Everything checked out fine. Early the next morning Franky seemed fine, but by noon his breathing sounded rough. His temperature rose to over 107 degrees! Since my other children were at home with me, I called an ambulance.

When we finally were able to see Franky at the hospital, they told us he was dying. The pediatrician met with us to explain that the x-rays showed a mild case of pneumonia. She felt that either the bacteria had entered his bloodstream causing overwhelming blood poisoning or it was meningitis. His white blood count was low which meant he wasn't fighting it. She didn't give us much hope. He had a seizure that lasted about an hour, and then he fell asleep. A short time later Franky decided to go to heaven even though they tried briefly to resuscitate him.

Our friends, our church, the East Texas Angel Network, and even total strangers rallied around us. We had a beautiful funeral that, thanks to the Angel Network and our church, cost us almost nothing. Their support continues to see us through.

It has not been easy losing our "baby." We loved him dearly. I never really minded carrying him, feeding him, cleaning up after him, giving him medicine, going on constant doctor visits, or any of taking care of any of his needs. But when he started suffering, I couldn't bear that.

We know he is in heaven, where there is no more pain or suffering. I see him talking, taking his first steps, running, and jumping. I would never wish him to come back, though I miss him terribly. Sometimes I wish I could hug him one more time, run my fingers through his hair, and kiss him. He is in a better place. I know I will see him again some day.

At Franky's funeral the church was nearly full. Many people took off work just to come.

They all did this for a boy who never spoke a word to any of them, but something in his life impacted their lives. I know that without our church, we could have never made it through this loss. I encourage you other parents who want to find this kind of church community not to give up. Keep looking until you find a church that can make a place for you, your family and your child with a disability.

Parents Share Early Experiences at the Parent Summit

By Paige Parrish, Parent, Tyler, TX
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Editor’s note: There are laws, statutes, and memorandums of understandings between agencies that are written to insure that families of children with disabilities get the services they need in a timely fashion. Unfortunately they can be pretty meaningless if the public is unaware of them. Typically the public only becomes aware when an issue touches their lives in a personal way. Most of the people in Texas will not experience the impact of a visual impairment on their child’s lives. Since most of you reading this newsletter have been touched with the issues of blindness it is up to you to help keep the public aware. As the parents who gathered for the Parent Summit in Austin learned through their discussions, there is definitely a role for parents to play in helping the general public learn about blindness and visual impairments and the resources that are available in Texas.

An extraordinary event occurred on April 9th at the Texas School for the Blind and Visually Impaired in Austin, Texas. Experts from around the state convened to discuss issues that affect our children. There were no chiefs of state or heads of government agencies attending this event, just the heads of households. Parents of children with visual impairments from around Texas were convened to give our valuable opinion about how to make a better future for our children. Under the guidance of a facilitator, we grouped geographically to identify existing services in our area. We brainstormed together to identify our needs and the needs of our children. The general consensus was that chief among all the needs we had was getting information about services and resources earlier in the life of our child. The stories we shared about our experiences with the initial diagnosis and the early experiences that followed were all too familiar. One phrase that continued to pop up like a jack-in-the-box was “first point of entry.”

I am the parent of a seven-year-old visually impaired child named Alexandria. My “first point of entry” was at the office of my daughter’s pediatrician. After noticing some irregular eye movements during a checkup he referred us that same day to a neurologist at a children’s hospital. I couldn’t believe it when they told me they suspected that my two-month-old baby had a tumor on her optic nerve. After conducting more tests, they determined that this was not the case and sent me to a pediatric neuro-ophthalmologist. There it was decided that Alex did have a severe visual impairment. Her bizarre eye movements, they felt, were indicative of a

childhood cancer called neuroblastoma. This is the diagnosis we lived with for about a year.

Needless to say, the vision issue definitely took a back seat to cancer. Our family was emotionally devastated. Not once did any of the medical professionals say, “Hey, this is a really difficult time for you. Let me hook you up with the right people to make it a little easier.” Financially this was also quite a burden on our family since my husband was a medical student. The stress and strain on our marriage, I don’t think I even have to mention. Here we were a part of the medical community, but no physician referred us to someone who could give us direction and support! My husband and I are fairly intelligent people, but we did not know what to do.

I was in denial, and my husband naturally focused on the medical aspects of our daughter’s condition. Had we been referred to a social worker, I think we would have been given some guidance about what to do. Things like applying for SSI benefits or getting services from Texas Commission for the Blind probably would have made our lives a lot different. (*Editor’s note: The Disability Determination Unit of the Social Security Administration forwards all applications with the diagnosis of blindness to the Texas Commission for the Blind for rehabilitation services.*)

The good news was the cancer did not thrive, but the bad news was the visual diagnosis looked grim. The doctor called it Leber’s Congenital Amaurosis and told us in a cold, clinical tone, “Your daughter’s condition will end in total blindness, so you should prepare her for a school for the blind.” The doctor did not seem to consider my frame of mind. My reaction was, “My daughter is blind and now you want me to send her away!”

I continued to have a healthy dose of denial and did not ask any questions. I did not know that all babies with a hearing or vision loss could receive early intervention services in their home. I did not know there are federal and state regulations requiring all professionals to refer children, birth-three, with a developmental delay to Early Childhood Intervention (ECI). Based on all the similar stories that were shared at the Summit, apparently other parents and professionals didn’t know this either. As a parent I want to know if it is possible to tell physicians that referrals are not just a vague, ethical obligation? I feel they need to be held more accountable for helping parents and others connect to these other support resources. As an enlightened parent I can do my part by sharing my knowledge and experiences within the medical community. I can let them know that I am available to offer other parents support and information when they face similar concerns.

At some point I finally called the Texas School for the Blind & Visually Impaired and was given support, referrals and a world of information. After ECI evaluated Alex, the lack of early intervention in my daughter’s life was evident. She displayed poor overall muscle tone, especially in the hip flexor area. This occurred because her vision loss reduced her motivation to move and also made her fearful of movement. She was very passive and quite content to sit

in one spot and play with one toy. ECI referred me to my local school district to receive vision and orientation and mobility services.

As parents talked throughout the day-long Summit, a number of things became clear to me. I'd like to share these insights with you other parents who may be reading this article. First, investigate what resources are available to you and your child. Make sure you know the laws that can impact your child and your family. Learn about the appropriate channels for initiating change. Find out your legislative representatives' names and how to contact them. Remember that one parent can make a difference.

By attending workshops and conferences I am learning about the needs of my child. My daughter is out there advocating for herself at the age of seven! I hope that I have been a good example for her through my efforts to make a difference in the lives of visually impaired and blind individuals.

I look toward the future with much optimism realizing there is a lot of work to be done. I hope I can encourage you to become knowledgeable about the issues surrounding the education of your child. I am grateful for the opportunities I have had to educate myself. I feel that I have fulfilled a vision that Phil Hatlen has of parents of walking into an ARD meeting as equally informed as the educators about the educational needs of their child with visual impairments.

At the Summit the camaraderie between the parents was impressive. A sort of kinship was formed with the sharing of experiences and information. The incidental tips I got from parents that were farther down the road will come in handy. We discussed the benefits of forming parent support groups. I know this is not always feasible with the busy lives we lead, but at least extend yourself. Offer your name as a contact for other parents who may just be learning about their child's visual impairments. Let your TCB caseworker, social worker at your local hospital, your ophthalmologist, your pediatrician, and your vision teacher know that you are willing to visit with another parent or share information about services you have found in your area. It is my dream that one day all these professionals will work more collaboratively together to make the lives of our children meaningful and successful.

Future Horizons Review

By Jean Robinson, VI Outreach Family Support

After attending two "Future Horizon Retreats" (one in Dallas and one in Corpus Christi) I know firsthand that the time and money that goes into making this event happen is time and money well spent. I know this because of my personal experiences at the retreats, but also from the feedback I have received from the participants. About sixty families with visually impaired children spent a weekend together learning about themselves and others and also

having a great time. In Corpus Christi there was an opportunity to tour the aircraft carrier, S.S. Lexington, and see the ocean. In Dallas we paid a visit to the Arboretum gardens. In both locations we had opportunities to swim, play Bingo and other games, and talk to adult mentors with visual impairments. The families who attended express the benefits of this experience best:

“Our 5-year-old enjoyed learning how she could help her big sister.”

“I gained insight into common problems faced by all parents of visually impaired.”

“Our family gained better understanding of my son’s disability.”

“My daughter enjoyed the interaction with the other visually impaired kids and it increased her confidence.”

“Seeing college students with visual impairments helped my daughter build future goals.”

“I realized how my son can go by himself a lot more than I would let him!”

“My son gained confidence and hope.”

“His brother seemed to understand him better.”

“I feel more secure regarding Ben’s future.”

“My daughter is more open to accomplishing more.”

“My son’s abilities and belief in his capabilities has greatly expanded.”

“Elizabeth enjoyed socializing with the other adults and kids with her same disability.”

“My daughter was proud of being the one responsible for our family getting to go on this trip.”

“The guest speaker motivated us to think that Lauren could do anything, even be a parent.”

Personally, I will never forget the look of awe on a young brother’s face when he saw the ocean for the first time. He was so overwhelmed that he wasn’t even interested in eating!

Our next “Future Horizon Retreat” is in September in Galveston and will focus on children ages 6-9 with visual impairments. Remember I mentioned time and money? The money comes from a generous grant from the Texas Commission for the Blind. The time comes from many people and sources. If you are visually impaired and interested in being a mentor to these families contact me at 512-206-9418 or at <jeanrobinson@tsbvi.edu>. Hope to see you in Galveston!

Usher Teens and Families Come Together

By David Wiley, Transition Specialist, TSBVI, Texas Deafblind Outreach

During the statewide Symposium on Deafblindness held in Austin in February 1998, a group of parents who have teenagers or children with Usher Syndrome met and decided they would like to stay in touch with one another. Several of these families met together with Texas Deafblind Outreach later that year to plan how best to support and stay in contact with each other. They decided that they would like to have regular retreats for the entire family. The first Usher Syndrome Family Retreat was held in the summer of 1999, and was a successful and enjoyable experience for all. This year, on April 29 and 30, the second Usher Syndrome Family Retreat was held.

THIS YEAR'S RETREAT

Nine families met for the weekend in Austin where they heard speakers, talked to nationally recognized professionals, and had fun with one another. Texas Deafblind Outreach sponsored the event, and provided assistance with travel expenses to enable families from across the state to participate. Separate sessions were held for the young people with Usher, the parents, and the siblings. Some grandparents, and friends, and other family members were also in attendance. In addition to the breakouts for specific groups, time was planned for everyone to get together just to have fun.

The sessions for the teens with Usher were led by Harry Anderson and Jamie McNamara, and were based on the theme of leadership. Mr. Anderson is a counselor at the Florida School for the Deaf and the Blind in St. Augustine. He is also able to share his experiences as someone with Usher Syndrome, and the past president of AADB, the American Association of the Deaf-Blind. Ms. McNamara works in Shawnee Mission, Kansas as a Technical Assistance Specialist for NTAC, the National Technical Assistance Consortium on for Children and Young Adults who are Deaf-Blind. She also has the perspective of an adult with deafblindness. The teens learned about self-determination and leadership skills. They also shared their experiences and their goals. Several members of the group had met the previous year, and were able to catch up with one another. Everyone also got to make new friends.

The parents received information from Dr. Sandra Davenport, of Minneapolis, Minnesota. Dr. Davenport is one of the leading authorities on Usher Syndrome in the nation. In addition to workshop sessions, she met individually with the families to answer questions and provide in-depth information. The parents also heard from Brad Carlson, Deaf-Blind Specialist with the Texas Commission for the Blind, and learned about TCB services related to college and career planning. Jeff Anderson of the Southwest Collegiate Institute for the Deaf provided information about his school.

The siblings had a chance to share feelings about their families, and have their questions

answered. Roy Martz, a social worker from Texas School for the Blind and Visually Impaired, helped guide the discussions.

In addition to these learning experiences, there was time for socializing, swimming, games, and exploring the Internet. A highlight of the weekend was a series of short skits performed by Harry Anderson and his son, Jeff, which kept everyone laughing Saturday evening after dinner. When the weekend was complete, the response of the participants was positive, and plans were made to hold future Usher Syndrome Family Retreats.

GETTING A NATIONAL PERSPECTIVE

One outcome of this year's retreat is that a three-person team from Texas will be attending a national seminar on self-determination for teens and young adults who are deafblind. This event is co-sponsored by NTAC, and will be held in conjunction with the meeting of AADB in Columbus, OH. The team is composed of a teenager with deafblindness, a young adult mentor who is deafblind, and a professional from the state deafblind project. The young people have made a commitment to stay in contact after the workshop, and provide leadership to other young people in Texas.

USING THE INTERNET TO STAY IN CONTACT

Another outcome is the creation of an eCircle for Usher families. An eCircle is a private web site for a group of people with a common interest. For privacy, people can only access the site by invitation. This web site is a place to post announcements, have discussions, post photographs, and have real time "chats" with other circle members, among other features. Checking the site on a regular basis is one way to stay in touch, and support one another. If you have an interest in the eCircle, contact David Wiley or Kate Moss at Texas Deafblind Outreach. (Kate <katemoss@tsbvi.edu>; David <davidwiley@tsbvi.edu>)

Some teens and other family members from all over the state are also privately communicating through e-mail. Those who want a broader e-mail circle can find it through listserves that are organized across the nation. A listserv is an e-mail distribution list for people who share an interest. There is one very active listserv about Usher that is used primarily by adults with Usher Syndrome. There is another for teens with deafblindness. Information on being part of a list can be found through the DB-LINK site at <www.tr.wou.edu/dblink>.

CONCLUSION

Families including teens and children with Usher Syndrome in Texas have expressed an interest in remaining in contact and supporting one another. These families are spread throughout the state, but have been gathering for retreats, and staying in touch electronically. The next get-together for the parents has been planned as a part of the statewide Symposium on Deafblindness to be held in Dallas in on February 15-17, 2001. For more information about

Usher Syndrome, or the family activities, contact Texas Deafblind Outreach at Texas School for the Blind and Visually Impaired. If you are interested in speaking directly to another family, several families have expressed a willingness to be contacted. For Usher Syndrome, Texas families are finding support from one another.

Through a Teen's Eyes

By Wayne Cuthbertson, 19 year-old law student
at the University of Aberdeen, Scotland

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As a child, the fact that I have Moebius syndrome never troubled me at all. From a fairly young age, I have been aware of the fact that I am different. It never had a name; it was just there all the time. To me it was the things I could not do: I could not smile, move my lips, move my eyes from side to side or suck properly. I was just different from everybody else. There were always people who pointed at me, made jokes and comments, and tried to show up my deficiencies, but I let it all wash over me. I had lots of support, and I had a strong sense of self-worth and inner belief and confidence. I do not know when it happened, but suddenly when I started high school, among lots of new people and in a different place, the world seemed bigger and stranger, and infinitely more daunting. For the first time in my life, I was not just aware that I was different, I was acutely aware. Perhaps it is this increased level of consciousness that comes with adolescence that helped to shape me. Forget the warm hugs of your parents and the support of your friends. When you hit your teens, it is time to stand up and be counted as a person. Here is a little of what I have learned, and some advice I can give to anyone who has Moebius syndrome or any other disability.

1. You need to get over being so aware of how different you are, that it makes you shy, or overly sensitive. Believe that you are a beautiful person; believe in yourself.

2. Never forget that we are each our own individuals formed in a singular and unique way, and never let anyone say you are not special. There is no such thing as perfection. Perfection is an unattainable ideal which can be striven for but never achieved. If anyone tells you that you are not "normal" ask them what "normal" is. That often makes them think, but some people are remarkably cruel at this age. If they still persist, tell them: "I don't care what

you think, none of us are ‘normal’ we are all different and beautiful in our own ways.” If they laugh at you, then have a laugh yourself as they are probably so immature, close-minded and wrapped up in their own prejudices that it isn’t really worth caring about what they think.

3. *When you talk face-to-face with someone, maintain eye contact.* It oozes self-confidence, and people will respect that. Also remember that it is not always how you say things, but what you say that counts. If you can come to terms with being different, then so can other people. Just believe in yourself.

4. *It all comes down to confidence.* This is what getting through your teens is all about. You need to love the person you are. Stand up for yourself and never let anyone brush you off. Most of all, be assertive. Show people what you are like on the inside, and you will find that they will like you more than you think. Have confidence in your abilities, and let nothing stand in the way of what you want in life. Love and believe in yourself, and you will go a lot further than you think.

5. *Making friends can get much tougher as you mature.* As you become aware of how different you are, don’t be afraid to put yourself out there when you meet someone new. If you can’t lift your head up and offer them a warm smile, let your inner warmth come out in other ways. Be honest and open - other people will always respect that. Be confident when meeting people. Getting involved in lots of group activities and sports, if you are able, will expose you to new people all the time and allow you to grow in stature as a person. Try something new!

6. *The other sex: Don’t be afraid to talk to the other sex.* If you have confidence in yourself then anyone will like you. But no one who cowers away in the corner ever has any success. If someone likes you, then they will like you as the person you are. If they don’t like you because of the condition you have, then they are probably not worth knowing anyway! Try not to be too shy, although I know it can be very difficult. Now, kissing for someone who has Moebius syndrome is quite a proposition. I mean, if you can’t move your lips, how can you kiss someone properly? The simple answer is you can’t. However, you would be surprised at what can be achieved with a little effort. Kissing is possible just don’t be too embarrassed to try. Use what abilities you do have the best way you can.

7. *The teen years can be a hard period.* It was hard for me. Come to terms with it and with your place in the world. I have always found that it helps to be able to just have a quiet “thought” about things to yourself. Take a step backward, and upward, and have a look around; you will often see yourself and other people in a different light.

8. *Life is a constant learning process.* There is no such thing as failure, only feedback.

9. *There were times during my teens when I thought I was the only person in the world like this, and I was just being punished.* I often felt like, “Why do I bother when people only

seem to try and knock me down?" Well, I have been there and have gone through it, and I am 10 times better for it. I am nowhere nearly as shy as I used to be. (Shyness isn't necessarily a bad thing. It is often a sign of sensitivity.)

10. *Enjoy your teens.* While it can be one of the hardest times in your life, it can also be one of the happiest.

Much of this advice may apply all throughout your life. During your teens, however, you are more aware of your own idiosyncrasies, making this time even more difficult. Never forget those who love and support you, but that they can't be there forever. That is why we all need to build our futures through our own strengths and courage.

Parents may wonder how they can help their child to do this. It seems to me the greatest thing parents can give to their children who have Moebius syndrome, or any other disability, is love. My mother never treated me any differently than my brother and sister - she loved me just the same. Giving children the strength and confidence to love the people they are and believe in themselves will get them through the most difficult times. This will help them become more independent and able to tackle the world on their own. Parents are a solid foundation for children to build from. With a loving parent who encourages, supports, and believes in them, I see no reason why children who have Moebius syndrome, or any other disability, cannot achieve a great deal. I don't intend to let it hold me back.

Many will tell you that people who have Moebius syndrome can't smile, but I have never believed them. I can't physically smile, but I have been smiling all my life. I feel warm and happy and joyful inside - isn't that what smiling is all about? People who know you well will know when you are smiling. I have always believed that while I can't make my lips form the shape, everything else is there.

Toilet Training Children with Deafblindness: Issues and Strategies

By Craig Axelrod, Teacher Trainer, TSBVI, Texas Deafblind Outreach

A version of this article first appeared in the October 1992 edition of P.S. NEWS!!!

Editor's note: This article is based on a workshop presented by Ray Condon in July 1992. Additional information about routines can be found on TSBVI's website, <www.tsbvi.edu>. See <http://www.tsbvi.edu/Education/vmi/routines.htm> or <http://www.tsbvi.edu/Outreach/seehear/archive/routine.html>.

Independence in toilet training is a milestone celebrated by the children who achieve it and their grateful parents. Families and educators often experience frustration, disappointment

and resignation when faced with the challenges of toilet training a child who is deafblind. Many factors can influence toilet training efforts; such as physical maturity, awareness of self and the environment, positive relationships with other people and the ability to communicate with them. All factors must be considered when toilet training a child who is deafblind. A team approach is also essential for success. People who can contribute important knowledge and experience to a team include the child's parents and siblings, classroom teacher, intervener, VI teacher, communication specialist, OT, PT, school administrators and a medical doctor.

COMPARISON OF TOILET TRAINING PRACTICES

Toilet training approaches for children with disabilities often differ drastically from those used with nondisabled children. It's suggested that a "normal" child be taught in a low-key manner, with social praise and reinforcement. Books, verbal explanation, modeling and observation are used to teach language concepts, responsibility, competence and independence. The child sits on the toilet for short periods of time. If there is resistance to toileting, training efforts are postponed. Use of punishment is not recommended, and can be considered harmful. In contrast, the best known programs developed for children with disabilities recommend rigid training procedures to be followed intensively for several hours every day. Sessions on the toilet may last up to 25 minutes of every half hour. Motivators might include food, toys and other primary reinforcers, or secondary reinforcers such as tokens, adhesive stickers and checkmarks. Overcorrection (for example, cleaning the entire floor of a room where a toileting accident occurs) and positive practice (repeating the steps of a toileting sequence multiple times) are procedures often used to end toileting accidents. Resistance to toilet training is met with stronger rewards or punishers. Why are our educational strategies with disabled children so much more "heavy-handed" than the ways we teach children without disabilities?

PROBLEMS WITH TRADITIONAL PROGRAMS

There are drawbacks to many of the toilet training programs developed for children with disabilities.

MANY OF THESE PROGRAMS HAVE INTENSIVE TIME REQUIREMENTS

The most popular of these programs requires an intensive commitment of time and attention from those working with a child. In a school setting this is sometimes possible because several adults share the responsibilities of managing a classroom and its students, or a single adult is responsible for providing one-on-one instruction to the student who is deafblind. At home, however, a family often has fewer people and limited time to devote toward this kind of effort.

TOILETING PROGRAMS HAVE A LOW SUCCESS RATE

In acquiring any new skill, a learner must consistently experience a 70% success rate (7 correct responses to every 3 mistakes). The obvious toileting mistake is an accident. A less

obvious mistake is sitting on the toilet without “results.” Toileting programs that incorporate long, unproductive commode sittings increase the percentage of errors, and ultimately make learning more difficult.

CHILDREN DON’T MAKE THE CONNECTION BETWEEN THEIR BEHAVIOR AND THE RESULTING CONSEQUENCES

Children with deafblindness often have limited communication skills. They may not independently distinguish important from unimportant information or see relationships between their behaviors and the resulting consequences. They might not understand that overcorrection or positive practice are responses to a toileting accident. While an adult is responding to wet or dirty pants, the child might think the consequence is related to something else that coincidentally occurred at the same time, such as engaging in a self-stimulation behavior, patting the cat, or playing with a light switch. If independent and consistent toileting is the team’s goal, requiring a child to repeatedly “practice” the toileting sequence or clean up the floor will not achieve this result. These activities don’t teach the desired behavior, which is successfully voiding in the toilet. It is good for children to develop a sense of responsibility about caring for themselves and their environments. There are also many naturally occurring opportunities to practice removing and putting on clothes, such as before bath time or during morning dressing. Implementing overcorrection or positive practice procedures as consequences of accidents, however, will not teach a child to use the toilet appropriately.

OVERCORRECTION AND POSITIVE PRACTICE FEEL LIKE PUNISHMENT

Another problem with consequences such as overcorrection and positive practice is a person’s understandable attempts to escape and/or avoid the people, places and activities associated with what is seen as punishment. By making toileting an unpleasant experience, a team may be sabotaging its goal. An additional consideration about punishment is the message it sends: that these are acceptable ways to interact. Children often imitate other people’s behaviors. It’s important that we behave towards them as we want them to behave toward others.

DEVELOPING A TOILET TRAINING ROUTINE

Toilet training follows this general sequence. First, a child’s bodily maturity and regularity indicate readiness for toilet training. Then, other people begin anticipating the child’s need to go at predictable times, and schedule train. Finally, the child learns to recognize the voiding urge, and responds appropriately by going to the toilet or asking to go.

DETERMINE READINESS

“Is my child ready to be toilet trained?” Readiness can be assessed in several ways. A child’s body must be mature enough for toilet training. Physical maturity for training readiness typically occurs in nondisabled children between 18 and 30 months. Determine maturity by observing the child’s behavior. Behavioral indicators for bowel training include regularity in

bowel movements and no accidents while the child sleeps. Readiness for bladder training is indicated when the child remains dry during naps and regularly stays dry for 1.5-2 hours. Initial training with a nondisabled child may take from 5-10 months. These and other toileting norms such as a child's awareness of the need to go, the motivation to become toilet trained, and so forth; can only be suggested by age ranges. The order in which some norms are demonstrated (**Chart 1**) may also vary from one child to another. Children mature at different rates. In addition, a child may experience setbacks due to circumstances such as an illness, changes in daily routines or a new sibling at home.

Chart 1 - General Toileting Norms

- Sphincter and bladder control generally follow this sequence: control of bowels while asleep, control of bowels during waking hours, control of bladder while awake, and finally, bladder control at night.
- A child who has regularity with bowel movements and no accidents while asleep may be ready for bowel training.
- A child who remains dry during naps and regularly stays dry for 1.5-2 hours may be ready for bladder training.
- A child's age of training readiness may range from 18-30 months.
- Initial training may take from 5-10 months depending upon the child's physical maturation and motivation.
- It is not uncommon for children to experience setback or regression during illness, major changes in their daily routines, when starting school or getting a new sibling.
- Some children may not become completely trained in the daytime until age 5, or at night before age 7.
- Girls learn faster and earlier than boys.
- Children become aware first of having eliminated, then that they are in the process of voiding, and finally recognizing the voiding urge before going.

Another indicator of readiness is the willingness and ability of parents and school staff to invest time and energy into toilet training their child. Since successful implementation of a toilet training program requires consistency and cooperation between home and school, everyone on the team must be committed to this effort.

Also, remember that the toileting "experts" don't always agree about a child's readiness.

Find out about past toilet training efforts. What was successful and where were the problems? After soliciting and considering the input of all its members, your child’s educational team can make an “expert” decision about whether to begin.

Even if the team decides to postpone toilet training, many of the skills needed during toileting, can start to be worked on in a diaper changing routine. Every activity in which your child participates should be seen as a teaching and learning opportunity for building useful concepts and important skills related to toileting. Learning concepts such as “wet” or “dry,” participating in dressing activities, asking for assistance, learning routes and independent travel skills, and so forth can be worked on throughout the day in a variety of activities.

GATHER DATA

After deciding to begin toilet training, find out when your child is wet and/or dirty and dry. A frequent diaper or training pants check (every half hour, or more often if needed) for at least 14 days will be necessary to identify a pattern of elimination. Factors such as amount of liquid intake, illness, sleep and routines can affect regularity. Look for special behaviors your child might demonstrate immediately before urinating or having a bowel movement. Share this information with other team members. Collecting information requires time and effort, but it will save time in the long run. Since a 70% success rate is necessary for learning, it’s important to identify times in a day when a child most likely needs to “go,” and target those times for toilet training. While children often have bowel control before bladder control, bladder training is usually worked on first because there are more opportunities in a day to be successful.

Using a data collection method such as the one shown in **Chart 2** can be very helpful. This baseline information will also help your team determine how well its toilet training program is working. Compare it with data that’s regularly collected after toilet training has begun.

ASSESS YOUR CHILD’S TOILETING ABILITIES

Clarify the sequence of steps a nondisabled person follows when using the toilet. Informally assess your child’s ability to complete each of those steps. Identify steps that are completed independently, then distinguish between steps that can be taught without additional changes and those requiring adaptations.

SELECT OBJECTIVES

Every child has unique learning needs, specified in an IEP as goals and objectives. Although they are artificially separated in the IEP, many skills are often used together to complete an activity. When developing a toilet training program, it’s important to remember that voiding in the toilet is only one of several interrelated skills needed to complete this activity. Knowing where the bathroom is and how to get there, undressing and dressing, getting on and off the commode, and requesting assistance are examples of orientation and mobility, self help,

Chart 2 - Toileting Data Collection Chart

Key: UT- urinated in toilet UO - urinated off toilet
 BT - b.m. in toilet BO - b.m. off toilet N - on toilet, did nothing

PROGRAMMING

Time A P	Week of _____							Week of _____						
	Mon	Tues	Wed	Thur	Fri	Sat	Sun	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12														
12:30														
1														
1:30														
2														
2:30														
3														
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11:30														

motor and communication skills that contribute to successful toileting. Select 2 or 3 objective-based skills from the IEP that are necessary or helpful in teaching those steps, and can be naturally incorporated into the routine sequence.

IDENTIFY ADAPTATIONS

Identify the adaptations that will be needed to support your child's completion of steps in the sequence more independently, such as a calendar system to schedule and communicate toileting time, or pants with an elastic waistband for an older student who cannot zip or snap. Since it's not possible for a small child to struggle at maintaining balance on the commode while at the same time relaxing to use the toilet, consult with your OT or PT to see if adaptive seating is needed. Consider your child's size and dimensions when deciding the specific seating requirements (**Chart 3**).

Chart 3 - Seating Guidelines

Goals

- Child should be comfortable, balanced and secure.
- Child should use a minimum of conscious effort and physical energy to stay seated.

Principles

- Pelvis should be stable and in a neutral position, with body weight evenly distributed across buttocks and thighs (hips and knees flexed at 90 degrees).
- Trunk should be symmetrical and in midline.
- Feet should be supported on floor or stool (ankles at 90 degrees).
- Head should be in line with trunk and in a neutral position.
- Forearms can rest at elbow height.

Proper Measurements for Chair or "Potty Seat"

- Seat depth - length of child's thighs (distance from above knees to buttocks).
- Height of chair seat - length of child's shins (distance from just below knees to heels/soles of feet).
- Chair back - length of child's back (tailbone to shoulder girdle).

CONSIDER APPROPRIATE TEACHING STRATEGIES

Because your child may have acquired some skills and not others, the support that is needed could change from one routine step to the next. We often, however, give our children

the same level of support throughout an activity, regardless of their ability to complete some steps with more independence. Consequently, they may become prompt dependent by learning to wait for our prompts before beginning or continuing a sequence. To prevent this from happening, keep an array of teaching strategies in mind when designing a toileting routine. Incorporate the approaches that are most helpful into the routine you use for instructing your child. Examples of strategies include:

- The hierarchy of prompts - from least intrusive (object needed in routine, picture, point, sign, etc.) to most intrusive (hand-over-hand, hand-under-hand, physical prompt, etc.);
- The progression with which prompts are given - independent attempts followed by increasing adult support (least intrusive to most intrusive), or intensive support provided initially, then faded (most to least);
- The timing with which prompts are given - immediate redirection to minimize potential distractions and maintain focus on the sequence, or “wait time” to encourage self-initiation and acknowledge the need for processing.

Since our children (like us) have “good days” and “bad days,” additional support may sometimes be needed to help them successfully complete steps that are completed independently at other times. We must be attentive to their changing abilities and needs, and provide the support that is necessary at each moment.

PUT IT ALL TOGETHER

Write a toileting sequence for your child that incorporates any necessary adaptations the team has identified. Teaching strategies should also be reflected in the sequence steps and/or noted somewhere on the plan. Be sure the team agrees to a procedure that can be followed at both school and home. Consistency is essential. Plan with your child’s safety, security, self-respect and eventual independence as overall goals.

To begin, choose the two times each day, at home and school, that you have found your child to be most regular. Don’t be discouraged by the lack of immediate results. After the toileting routine is consistently followed for a while, your child will begin to anticipate the sequence steps. Expectation leads to participation. (If, however, your child still isn’t having success, review the routine sequence and consider making changes.) Be prepared to give immediate reward and praise for successful toileting. Select a reinforcement that is truly rewarding yet can be gradually faded over time. One child might enjoy flushing the toilet while another appreciates the overhead light flashing on and off. Do not punish for accidents, though participation in cleanup is okay. Continue collecting data to monitor your child’s progress and the program’s effectiveness. Gradually increase the number of daily toileting sessions, and generalize the routine into other places.

While developing a toilet training procedure that works on current needs, you should keep long-range expectations in mind. For example, if requesting to use the bathroom is an eventual objective, identify a way the toileting routine can be communicated by adults, with a sign, picture, gesture, physical prompt, or toilet paper roll. After learning that going to the toilet always follows this communication, the student can then be given opportunities to request the activity.

PROBLEM SOLVING

For solutions to some common problems experienced in toilet training, try the tips suggested below.

Problem: My child refuses to enter the bathroom, sit or stay long enough on the toilet (5-10 minutes).

Tips: Familiarize your child with the bathroom and toilet. Getting into the bathroom or briefly sitting on the toilet should be the first toilet training goal. Reward the smallest step toward that goal. Try to increase your child's performance each successive trip. Provide plenty of opportunities for practice every day. Be sure your child is well positioned, comfortable and secure on the toilet.

Problem: My child does not urinate often or becomes constipated.

Tips: Give your child plenty of fluids. Salty snacks, exercise and other physical activity sometimes help encourage fluid intake. Swimming is another good choice, as some children manage to drink quite a bit while getting a workout. Motor therapy programs and exercise can also increase your child's ability to push during a bowel movement.

For constipation problems, increase fluids and add more fiber to the child's diet. Fruits, except for bananas and apples, have a laxative effect. The following recipe was recommended by a family in *Exceptional Parent* magazine: combine 1/4 cup bran, 1 cup prune juice and 1 cup apple sauce. Mix well. Keep refrigerated. They gave their daughter 3 tablespoons of the mixture with breakfast and dinner, and also used an over-the-counter stool softener. Consult a doctor if the condition is chronic, or the child has frequent diarrhea. Doctors can rule out structural problems or blockages, and prescribe stool softeners or diet modifications.

Some children intentionally hold bowel movements because elimination is painful (i.e. a crack or fissure around the anus). Increasing fluid intake and using stool softeners may help. If your child is obviously experiencing pain, consult a doctor. Some medications have side effects that include constipation and the frequent urge to urinate. Consult with a doctor to determine if your child's toileting is affected by medication. Finally, some children withhold urine or bowel movements in reaction to trauma, or in response to punishing toilet training

programs, behavior programs or environments. They may try to oppose control through counter control efforts such as refusing to do what is expected. Even though an adult can force a child to sit on the toilet, it is impossible to make him or her use it. The long-term solution is to establish or reestablish an interactional bond. A positive relationship between the adult and child encourages cooperation. Giving the child positive ways to exercise control through choice making also builds trust and reduce power struggles. Adults who are warm, accepting and gentle will provide the type of atmosphere that motivates a child to learn.

Problem: My child does not relax on the toilet.

Tips: First make sure your child is positioned correctly on the toilet. (See **Chart 3.**) Interrupt and redirect a very active child to an alternative, more calming form of play or activity. There is disagreement about whether children should be allowed to “play” in the bathroom. The “no play” advice is to keep a child focused on the bathroom’s primary purpose. Some children, however, may need a positive way to structure their “activity” of sitting on the toilet. Remove temptations like toilet paper rolls. Have pre-planned activities available for times when the child might “get into trouble.” Prevent problems. Provide close supervision and instruction, to teach the child what is permitted.

Problem: My child does not initiate toileting, but uses the toilet when taken by an adult.

Tips: Your child’s awareness of a full bladder or bowel is the best cue for self-initiated toileting. Some children become too engrossed in activities to notice. Others may lack the cognitive ability to recognize the voiding urge. Sometimes, when adults provide faulty instruction by not fading the use of prompts, their children become dependant on them to initiate the toileting activity. Encourage self-initiated toileting by gradually fading any necessary prompts. By teaching a child to use the bathroom after specific activities, those activities can become the reminders to go. Putting communicative reminders, such as pictures or object cues, in a child’s daily schedule or environment may also help.

Problem: My child is making no progress, doesn’t seem to understand the toilet’s purpose, is not bothered by being wet and has frequent accidents.

Tips: Take a break. Perseverance is necessary for teaching, but so is our responsiveness to feedback. The teaching sequence may not be appropriate or your child may not be motivated enough to succeed. Reassess the program and make adjustments. Whether you decide to continue toilet training or postpone it for now, always try to use an age-appropriate alternative to diapers, such as “Pull-Ups” or “Depends”.

Children at a sufficiently high cognitive and communicative level might understand picture, photograph or book explanations. Direct experience is the only option for children with more basic communication and cognition. They might, however, be able to observe other

children or family members model appropriate toileting behavior. Always change clothes in the bathroom after an accident. Deposit any “products” in the toilet.

A child may be making too many toileting mistakes, both accidents and instances when nothing happens on the toilet. Reduce the frequency of toileting visits, and determine if there is some pattern by keeping track of all eliminations. Watch for recognizable indications that the child is urinating or having a bowel movement.

As much as possible, maintain a regular routine or schedule with your child, especially with meals and snack times. Regulate and monitor what is given to eat and drink.

BOOK AND JOURNAL RESOURCES

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TOILETING EQUIPMENT RESOURCES

Flaghouse Inc.
150 N. MacQuestion Pkwy.
Mt. Vernon, NY 10550
(800) 221-5185

Gunnell
221 N. Water Street
Vassar, MI 48768
(800) 551-0055

J.A. Preston
60 Page Road
Clifton, NJ 07012
(800) 631-7277

Rifton Equipment for the Handicapped
Route 213
Rifton, NY 12471
(914) 658-3141

Minimal Losses...Major Implications

By Jenny Lace, Teacher Trainer, TSBVI, Texas Deafblind Outreach

Webster's dictionary defines minimal as "the least possible degree or quantity." Unfortunately this can imply that something is without consequence, insignificant, or requiring the least possible intervention. When it comes to vision and hearing losses this could not be further from the truth.

A dual sensory loss effects incidental learning. This is the learning that takes place just because you happened to see or hear something while you're hanging out, the way most of us learn most things. The problem with most incidental learning is that you can only learn what you can see or hear.

If you have a vision and hearing loss incidental learning is tremendously reduced. What happens when it is a peer's turn to read in a typical classroom, if you can't quite see him and you also can't quite hear him? You miss out on most of what he reads, comments he makes about what he read, and perhaps the feedback from the teacher and other students. When class discussions are out of sight and/or hearing range, the student with mild hearing and vision losses may spend more time daydreaming.

A common question that is asked is, "Won't the student let the teacher know if he can't hear or see clearly?" The answer is usually, "NO!" As Dr. Seuss might say:

You don't hear what you don't hear
And you don't know what you didn't hear....
You don't see what you don't see
And you don't know what you didn't see!

Do you know that a student can be on the deafblind census if he has documented hearing and visual losses that are minimal or mild? Even though these losses may not meet the requirements for auditory impairment or visual impairment if considered individually, if the combination of the losses adversely affects the student's education performance, they could be included on the deafblind census. When would that occur?

PROBLEMS OCCURRING WITH A MILD VISUAL IMPAIRMENT

A mild visual impairment is not easy to quantify. We generally think of someone with a visual acuity of 20/60 – 20/100 as mildly visually impaired. However, someone with Retinitis Pigmentosa might have 20/20 vision and better than 30 degrees of field vision and not qualify for vision services. This student would probably do fine visually. That is until the lights dimmed and the overhead went on or until they came inside from the bright sunlight into a dark hallway. Then they would experience visual impairment that was fairly significant for a time.

Another scenario would be the student who had vision only in one eye. Normally that wouldn't be a problem, but if he also had a hearing loss in one ear on the same side as the vision loss, sound localization would be hard, and travel safety might be impacted. Making a call on the impact of the vision impairment has a lot to do with how the child functionally uses his vision to do educational tasks. If a child is experiencing educational difficulties that appear to be related to problems with his vision, he should be seen by an ophthalmologist and possibly referred to the vision teacher for a functional vision evaluation and learning media assessment. If the child has a hearing loss, even a minimal one, and is experiencing difficulty in school, we would encourage the school to complete a functional vision evaluation and learning media assessment. There may be a need to make some specific modifications in programming or materials, even if the child does not need direct vision services. Part of the reason we say this has to do with the impact of the hearing loss. Please read on.

PROBLEMS OCCURRING FROM A MINIMAL OR MILD HEARING LOSS

A minimal or mild hearing loss would fall into the range of 16-40 dB. Even without a vision loss, a slight hearing loss can cause a number of significant problems, especially in an educational setting:

- Problems hearing faint or distant speech
- Problems hearing subtle conversational cues
- Problems tracking fast paced conversations
- Problems hearing the word-sound distinctions

What kind of impact might this have on the mildly hearing impaired student who has a vision loss in a typical classroom?

TROUBLE HEARING FAINT OR DISTANT SPEECH

If a student has trouble hearing faint or distant speech, more than 25% of classroom instruction could be missed. (Flexer, 1997) Add a vision loss and imagine the percent of missed instruction that would likely occur. The child with a mild vision impairment and mild hearing loss probably relies on the information he can pick up from watching the speaker's lips to confirm what he thinks he is hearing. This is especially true if he is not using a hearing aid. Distance is his enemy for both his vision and his hearing.

MISSING SUBTLE CONVERSATIONAL CUES

Students with minimal or mild hearing losses often miss subtle conversational cues that cause them to respond inappropriately. They may appear immature and be more fatigued than peers with normal hearing because of the extra effort they make to hear. (Flexer, 1997) Students with mild vision and hearing loss miss out on this information, too. They also experience added stress and may appear socially immature. Not only can they miss auditory information;

they may also miss additional conversational cues of a visual nature such as facial expression or gestures because of the vision problems. On top of that, their ability to use speechreading to support what they are hearing is impaired in many instances because of the vision problems.

PROBLEMS FOLLOWING CLASSROOM DISCUSSIONS

Another issue for the student with any type of vision and hearing loss is trying to follow a fast-paced conversation of a typical classroom discussion. About the time you locate the speaker and get focused auditorily and visually, he is no longer speaking and the girl behind you has the floor. You shift around to see her face, which you can actually see pretty well and you can also hear her pretty well. After about five seconds the teacher, who has moved to the window aisle, responds. She happens to be in front of the window with the sun coming in and beside the rattling air conditioner. After about twenty minutes of this activity imagine the impact on the student's attention and behavior. This also has great impact on his ability to participate in many types of social and extracurricular activities.

MISSES MORPHOLOGICAL MARKERS FOR PLURALITY, TENSE, POSSESSIVENESS

Try a little experiment. Put some earplugs in your ears. Have a friend stand across the room and in a quiet conversational voice say a series of words like, "hit, hitting, hits, rat, ram, dogs, dog's, dog, see, sees, seen." Did you hear all the different final sounds or did the words mostly sound the same? Now try it again, only this time, have a television or radio playing in the background. How did that work? Now do it without looking at his face. Next, add another friend across the room taking turns with the first speaker reciting a different series of words. What happens then? Chances are you could not tell exactly what words were being said with any accuracy. Imagine your entire day being like this. Do you think the student dealing with these conditions would be more fatigued and/or frustrated than the average hearing/sighted student? How would this impact his ability to get the information being presented?

MILD LOSSES EQUAL MAJOR PROBLEMS IN A TYPICAL CLASSROOM

SPEECH-TO-NOISE RATIO

The American Speech-Language-Hearing Association (ASHA) gives the following guidelines: ambient noise should be no louder than 30-35 dBA in an empty room; reverberation time should not exceed .4 seconds; Signal-to-Noise (S/N) ratios should be no lower than +15dB. Yet research has repeatedly found: the average unoccupied classroom (no children) noise levels are 41-50 dBA; the average reverberation times are .52 seconds; S/N ratios are only +4 dB, and may be worse than 0 dB. (Crandall and Smaldino, 1994)

Vision and hearing losses, even very mild ones, when combined can create some major problems. If you have a mild hearing loss you may not always function as if you have a mild hearing loss. How your hearing functions depends on the situation and the S/N ratio. We all have had the experience of being able to hear something without being able to understand what

is being said. Think of the drive-thru at MacDonald's or Jack-in-the-Box, a busy gate at the airport, or a noisy restaurant. Your ability to hear has little to do with how loud something is said, but rather how loud it is compared to everything else is in the environment around you.

Adults with normal hearing sensitivity and language abilities don't need as high of a S/N ratio as children. Typical adults need speech to be twice the sound pressure level of the background noise. (Flexer, 1997) Typical children need better speech-to-noise ratio than an adult to hear and develop the crucial word/sound distinctions of language. (Flexer, 1994) Persons with any kind of hearing loss need an even more favorable S/N (even when wearing hearing aids). Speech needs to be at least 10 times the level of background noise for them. (Flexer, 1997) If you factor in noise, reverberation, and frequent changes in teacher and pupil locations in the average classroom, the typical speech to noise ratio is less than ideal even for the child with normal hearing.

While we are mentioning reverberation or echo, did you know that longer reverberation times reduce the signal-to-noise ratio? (Scott, 1997) Reverberation time increases with high ceilings, bare walls, and hard-surfaced, uncarpeted floors. Think about the design of most classrooms, especially in older buildings.

BUSY VISUAL ENVIRONMENTS

Although there is not an equivalent vision-clutter ratio, there is a similar phenomenon that occurs. You know it well, too. Think about the last time you were in an unfamiliar store trying to find a specific item or the last time you had to find a friend in a crowded room. Figuring out where and what to look at is tricky. If there is a lot going on visually and you can't see anything very clearly, do you find yourself getting frustrated or feeling overwhelmed? Now look at the typical classroom. Is it a busy place visually with lots of clutter and competing visual demands?

LET'S MOVE THAT CHILD UP FRONT

A typical remedy for a child who does not hear very well and does not see very well is to move him up front, so he will be closer to the teacher. She is the learning signal we most want him to pick up, right? Well, not necessarily, not in a group discussion. This solution also assumes that the teacher is nailed to the floor in front of the child. How many teachers do you know who teach that way? Besides all of that, you are required to periodically look at your book, a handout, and the overhead or map. Preferential seating is a less-than-perfect solution for this child.

PROBLEMS AND SOLUTIONS

HELPING THE CHILD WITH COMBINED MILD OR MINIMAL HEARING AND VISION LOSS

There are several things that should be considered for this child. First of all, has appropriate assessment been done to determine the impact of the vision and hearing loss on educa-

tion? Even if the ophthalmological and otological evaluations from the doctors do not qualify them as visually impaired or hearing impaired under SBOE definitions, education may still be impacted. A functional vision evaluation should be done. Specific hearing assessment related to listening in differing environments may also be helpful in evaluating hearing functioning for educational purposes.

Making simple and appropriate modifications to the classroom can also make a huge difference. Acoustic modifications can be as simple as:

- installing carpet;
- putting rubber tips or tennis balls on desk/table/chair legs;
- installing curtains;
- installing acoustical ceiling tiles;
- maintaining ventilation systems, doors, lighting, and windows.

PROGRAMMING

Additionally, a Sound-Field FM System allows for the control of the acoustic environment facilitating accessibility of teacher instruction for ALL children in the classroom. An assistive listening device may also be appropriate. Those students who do not qualify for special education due to a minimal hearing loss or because they have not failed enough may be able to qualify for S/N ratio enhancing technology through Section 504 of IDEA using “Acoustic Accessibility.”

In addressing mild visual impairments there are also some simple modifications:

- Additional time with “hands on” exploration in order to internalize what others grasp incidentally;
- Reduced visual clutter;
- Low vision devices;
- Eccentric and varied viewing positions and seating positions;
- Improved lighting and glare control;
- Reduced use of overheads and chalkboards unless the student has the information on paper in front of him;
- Additional staff to assist with accessing information in group settings;
- Use of strategies such as a talking stick or raised hands to control the pace of group discussions and to provide more clues to who is speaking.

CONCLUSION

The needs of the child with minimal or mild combined vision and hearing loss can be major. Too often, these children must fail to have the support and modifications they need in educational settings. Many of the things we can do to improve the classroom for these children will also improve the classroom for the other students as well. It is important not to let these children fall through the cracks and miss out on the education they need. They are just too valuable to our future to overlook their needs.

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The Thread: To Socialize or Not to Socialize

By Sheryl Burgstahler, DO-IT Director

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Editor's Note: If you would like more information about Disabilities, Opportunities, Internetworking, and Technology (DO IT) contact them at: DO IT, University of Washington, Box 354842, Seattle, WA 98195-4842, phone - (206) 685-DOIT (voice/TTY), or visit the website at <<http://www.washington.edu/doit>>.

A while back DO-IT Scholars, Pals, and Mentors addressed the following questions in an active discussion on the Internet.

PROGRAMMING

1. What does it mean to you to have a “successful social life”?
2. Why is it (or is it not) important to develop a successful social life in college?
3. What are strategies for developing a fulfilling social life in college?

Below are some of the responses.

- As far as social life, I can't stress enough the importance of at least trying to get out and be involved. It really doesn't matter in what - clubs, teams, friends, whatever... It won't be easy...but it's worth it...
- Social life in college is imperative for your own sanity and for learning how to interact with people. In many cases, people make lasting friendships in college.
- ...those that come out of college without social interaction will have trouble. We live and work in a world where groups of people solve problems - especially in the areas of science, math, and engineering. Therefore, these people coming out of college will have trouble succeeding because they do not have the higher social skills required in this situation. Yes, you learn academically in college, however, the social skills learned are more important...
- I found people to be a lot more open in college than in high school, and I learned about socializing with others in college, and am still learning in graduate school. In college, I made most of my friends in classes, in the dining hall, at the foreign language table, and at the Lutheran Ministry at my university. I am still in touch with several people I met during my college years.
- I think I've learned from being with people, too. Mostly it's made being with people much easier for me. I'm not so self-conscious or uncertain of myself. Friends have also reintroduced me to things like crayons and taught me card games and so on. Not only is it fun to hang out with people, but it's emotionally uplifting. Life wouldn't be as worthwhile without friends.

- I think college consists of both social and academic learning. As I look back on my undergraduate days, I remember a lot more social times with other people than I do lectures or exams. And I'm not really a people-person, either. I know I learned a lot from the social end of things. Some of that learning was painful, because when you make friends, people sometimes give feedback which you need but wouldn't otherwise get about behavior and attitude. This is part of people relating to one another, and causes necessary growth. Mostly though, socializing is fun, and being by yourself is lonely.
- College teaches you many things if it works right. How to interact with many people in many different ways and on many different levels, but it also gives you information and hopefully enhances problem-solving and thinking for yourself skills.
- In college one has the challenge of balancing academic demands with social pleasures. That is something that will be important later on, too.
- I believe that this type of socialization turns out professional associations that last. Now that I am a computing professional, these relations continue. We have careers in common, and I rely on others to give me important information. My friends also rely on me to feed them information.
- In many cases for blind people socializing is the key to academics...we need sighteds that are part of the class, in the same section of the book, listening to the same lectures, doing the same homework, to help us with them. With their help we can get the descriptions we need. Therefore, socializing is, as I have said, imperative. Academics is the road we use to get there. After academics or dorm life, we can branch out into wider social circles. It is a progression.
- Having a successful social life will make your college career easier for many reasons. First, with a social life, a person does not feel lonely because you have friends to talk to and listen to. Secondly, you can get help from your friends if you need help. For example, you can study those killer midterms with friends! Third, a person would have more chances to form a relationship which we believe is important to people. Fourth, it will make you a "well-rounded" person and most companies will look for that when you look for a job.
- I have seen people who had a good social life in life and college. This is a key skill that you need to learn in college. In your professional career, you need to do this with your career and family.
- In college and "real" life you need a lot of support to even survive on your own.
- My social contacts came from communities of shared interest. Pretty much any religious or political interest, extracurricular activity or hobby can work if you use it. For me, the debate team and the foreign language house provided communities where I felt accepted and had a good time.

- The interest...allows me to escape my label. I guess you get a chance to know a person spiritually first...
- Living in the dorms helped immensely in immersing me in the college social life. Without the contact in the dining halls, my social life would only have been half as good at best.
- My social life revolves mostly around people on my floor or in the NASA program. I'm in Interservice Christian fellowship, too, and know people in it, but I got involved in that through people on my floor last year.
- A lot of my social life surrounded my career goals. I wanted to be a programmer and hung around the computer lab - not exactly beer and pizza, but it was very social. I think I learned more from the other students than from my professors. There was great interaction and sharing of ideas and concepts.
- There are many strategies to fulfilling social life in college. A popular way is to join a fraternity or sorority on campus. Through this, you can get a lot of friends from your house. Second way is to join a club that matches your interest. I prefer this way because it matches your interests with other people. I have a lot of friends by joining a club. Third way, similar to joining a fraternity, is to live in a dorm. This is a good way for people who don't want to join a frat.
- Socializing that is connected to your schoolwork is very valuable, too. I made one good friend in college in a class we were taking together. Every week, we got together and worked on the homework together. The best part was that we were able to help each other, so that it was not one-sided. During my first year as a graduate student, I also frequently discussed problem sets with my classmates. This gave me good experience for collaborating with others on research.
- You just need to smile at people and look receptive. You should take some time to go to a common place in your dorm and talk to the people there.
- I think that blind people face the particular challenge of not being able to walk up to someone with whom they would like to talk unless they hear their voice or the person introduces him or herself. In the dining hall, for example, I always asked someone to help me find a seat, but that person would not necessarily know the people I liked to sit with, so it was a game of chance. Sometimes I met people, sometimes I happened to sit next to good friends, and sometimes I was unable to join in the conversations around me. However, by making friends in certain interest groups and arranging to meet friends for a meal, I was able to keep in touch with the people I cared about.
- I understand that for some people making friends is not that easy as it is for others. But if you would treat people in a friendly manner, they are going to treat you the same. Whereas, if you feel yourself so different from others and would not talk to them then you will find yourself totally out of place. Everyone is the same and different, too. This is what is so good about the world.

Texas Deafblind Census 2000

By Kate Moss, Family Support Specialist, Texas Deafblind Outreach

The 2000 Texas Deafblind Census has been compiled. Dr. Roseanna Davidson, Director of Deafblind Census Project at Texas Tech University in Lubbock has worked with the Regional Deafblind Specialists in each of the twenty Education Service Centers to collect and verify this data before submitting it to the Federal Census Project. Some of the ESC regions have piloted a process of collecting, verifying, and analyzing the data in an effort to develop a census collection process to make sure we know all of the children with deafblindness in Texas. Based on the Federal Projection of Number of Students with Deafblindness, a number derived by taking a percentage of all students receiving special education service, there should be between 920-1380 school-aged children (birth to twenty-two) who would be eligible as deafblind for educational purposes. The actual number reported on the 2000 Texas census is much lower than that, only 607 below the age of 22. One of our concerns continues to be the children who should be identified as deafblind and receive specialized supports and educational modifications not being identified. Additionally, many of the children on the census have vision and hearing loss that is suspected, but not adequately assessed. With the new Deafblind Specialists at the education service centers, our hope is these children will be found if they are out there. Here are a few basic facts from the 2000 Texas Deafblind Census.

Ages

1 yr. - 9	11 yr. - 35
2 yr. - 19	12 yr. - 45
3 yr. - 21	13 yr. - 31
4 yr. - 29	14 yr. - 39
5 yr. - 27	15 yr. - 32
6 yr. - 29	16 yr. - 27
7 yr. - 32	17 yr. - 29
8 yr. - 34	18 yr. - 31
9 yr. - 37	19 yr. - 28
10 yr. - 34	20 yr. - 22
	21 yr. - 17

Gender

Males - 344
Females - 263

Top Fifteen Etiologies

Prematurity - 100
Microcephaly - 30
CHARGE - 29
Menengitis - 27
Cytomegalovirus - 26
Usher Type 1 - 23
Hydrocephaly - 20
Congenital Rubella Syndrome - 18
Down Syndrome - 13
Usher Type 2 - 12
Head Injury - 12
Asphyxia - 11
Leber's Congenital Amaurosis - 10
Tumors - 7
Cornelia de Lange Syndrome - 6

SYNDROMES/
CONDITIONS

Vision Status

Better than 20/70 better eye to 20/200 - 119
Legally Blind (20/200
or less than 20 degree fields) -291
Light Perception only - 47
Totally Blind - 67
Further Testing Needed - 14
Tested Results Nonconclusive - 46
Not Tested at Risk - 13
Other or Information Not Given - 30
Cortical Visual Impairment - 159

Hearing Status

15-40 dB loss - 63
41-70 dB loss - 151
71-90 dB loss - 99
91+ dB loss - 108
Further Testing Needed - 39
Tested Results Nonconclusive - 64
Not Tested at Risk - 96
Information Not Given - 5
Central Auditory Processing Disorder - 57

Interesting Facts from the Year 2000 Annual Registration of Students with Visual Impairments

By Nick Necaie, Coordinator of Federal Quota/Annual Registration, TSBVI Outreach

The Annual Registration of Students who are Visually Impaired is the count of eligible students who are visually impaired in each school district of Texas on the first Monday in January. The date for this years Annual Registration was January 3, 2000. Here are some of the interesting facts we have learned about children with visual impairment in Texas.

SYNDROMES/CONDITIONS

- Total number of students registered = 6602
- Students listed in 1999 but not 2000 = 930
- New students added in 2000 registration = 1115
- Braille readers=356
- Large print readers= 1207
- Regular print readers= 1392
- Auditory readers= 421
- Non readers= 2235
- Number of infants= 600
- Number of preschoolers= 795
- Number of kindergartners= 341
- Number of Legally blind students= 4457

- Number of districts with only 1 VI student= 202
- Number of districts with 1+ VI students= 703
- Number of districts 3 or less VI students= 394
- Most VI students in a region -1372 in Region 4 (Houston area) .
- Least number of VI students in region - 76 in Region 9 (Wichita Falls area).
- Braille reading student at the Texas School for the Blind and Visually Impaired - 53.
- Number of students whose primary handicapping condition is VI= 3883. The first handicapping condition listed is VI. These students may or may not have additional handicapping conditions listed
- Number of students whose secondary handicapping condition is VI= 1514. The primary handicapping condition listed is other than VI.
- Number of students whose third handicapping condition is VI= 1002. The first two handicapping conditions listed are other than VI.
- Number of students who are VI only= 2329. No other handicapping conditions are listed.
- Number of students with 2 or more handicapping conditions= 4273.

Moebius Syndrome: A Life Without Smiles

Reprinted with permission from the Moebius Foundation

<http://www.ciaccess.com/moebius/front.htm>

Moebius Syndrome is a rare disorder characterized by lifetime facial paralysis. People with Moebius Syndrome can't smile or frown, and they often can't blink or move their eyes from side to side. In some instances, the syndrome is also associated with physical problems in other parts of the body.

The Moebius Syndrome Foundation is a nonprofit organization started by parents and people with Moebius Syndrome. We've come together to do what we can to fight back - by spreading the word among the medical and lay communities and by supporting research into the causes, treatments, and possible cures for Moebius Syndrome.

Moebius Syndrome is extremely rare. Two important nerves - the sixth and seventh cranial nerves - are not fully developed, causing eye muscle and facial paralysis. The movements of the face, blinking, lateral eye movements, and facial expressions are controlled by these nerves. Many of the other 12 cranial nerves may also be affected, including the 3rd, 5th, 8th, 9th, 11th and 12th.

WHAT ARE THE SYMPTOMS?

The most apparent symptoms are related to facial expressions and function. In newborn infants, the first sign is an impaired ability to suck. Excessive drooling and crossed eyes may be present. In addition, there can be deformities of the tongue and jaw, and even of some limbs, including club foot and missing or webbed fingers. Most children have low muscle tone, particularly of the upper body.

SYMPTOMS MAY INCLUDE:

- Lack of facial expression; inability to smile
- Feeding, swallowing and choking problems (sometimes tubes are necessary to thrive; be very careful with solid foods)
- Keeping head back to swallow
- Eye sensitivity due to inability to squint (sunglasses and hats are very helpful)
- Motor delays due to upper body weakness
- Absence of lateral eye movement
- Absence of blinking
- Strabismus (crossed eyes, correctable with surgery)
- Drooling
- High palate
- Short or deformed tongue
- Limited movement of tongue
- Submucous cleft palate
- Teeth problems
- Hearing problems (due to fluid in ears, tubes are sometimes necessary)
- Speech difficulties (especially with closed mouth sounds and sounds involving the lips)
- Minor mid-line anomalies

Although they crawl and walk later, most Moebius Syndrome children eventually catch up. Speech problems often respond to therapy, but may persist due to impaired mobility of the tongue and lips. As children get older, the lack of facial expression and an inability to smile become the dominant visible symptoms. Moebius Syndrome is sometimes accompanied by Pierre Robin Syndrome and Poland's Anomaly.

HOW DOES IT OCCUR?

Children are born with it. Although it appears to be genetic, its precise cause remains unknown and the medical literature presents conflicting theories. It affects boys and girls equally, and there appears to be, in some cases, an increased risk of transmitting the disorder from an affected parent to a child. Although no prenatal test for Moebius Syndrome is currently available, individuals may benefit from genetic counseling.

HOW IS IT TREATED?

Infants sometimes require special bottles (i.e. Haberman Feeder) or feeding tubes to maintain sufficient nutrition. Strabismus (crossed eyes) is usually correctable with surgery. Children with Moebius Syndrome can also benefit from physical and speech therapy to improve their gross motor skills and coordination, and to gain better control over speaking and eating.

Limb and jaw deformities may often be improved through surgery. In addition, plastic reconstructive surgery of the face can offer benefits in individual cases. In some cases, nerve and muscle transfers to the corners of the mouth have been performed to provide an ability to smile.

HOW CAN I HELP?

One of the most frustrating aspects of coping with Moebius Syndrome is the surprising lack of awareness among physicians and nurses. It occurs so infrequently that many children go undiagnosed for months and sometimes years after birth. Parents and those affected spend a lot of time and emotional energy explaining and re-explaining this rare condition.

The rarity of Moebius Syndrome becomes, in effect, an additional complication of the disorder. Because so few members of the professional and lay public have even heard of Moebius Syndrome, medical and social support, as well as reimbursement from insurance companies are severely limited. This lack of support services puts additional burdens on individuals and their families in their attempts to cope with Moebius Syndrome. Lack of awareness also plays a role in limiting research into potential treatments and cures for Moebius Syndrome.

THE HABERMAN FEEDER

In some cases of severe feeding problems, such as those caused by Pierre Robin Syndrome or Moebius Syndrome, the Haberman Feeder offers an alternative to enlarged and/or extra holes in the nipple and nasogastric tubes.

Invented by the mother of a little girl with Pierre Robin Syndrome, the nipple rewards even the slightest effort from the baby's tongue or gums. If the baby cannot nurse at all, one can squeeze and release a limited volume of milk from the reservoir into the baby's mouth.

To order the Haberman Feeder call (800) 435-8316, or fax (815) 363-1246.

DESCRIPTION OF THE 12 CRANIAL NERVES

Moebius syndrome impacts the 6th and 7th cranial nerves - they are not fully developed, causing eye muscle and facial paralysis. The movements of the face, blinking, lateral eye movements, and facial expressions are controlled by these nerves. Many of the other 12 cranial nerves may also be affected, including the 3rd, 5th, 8th, 9th, 11th and 12th.

- 1st = Olfactory nerve - relays smell
- 2nd = Optic nerve - transmits visual information
- 3rd = *Oculomotor nerve - supplies external muscles of the eyeball with motor and sensory fibers*
- 4th = *Trochlear nerve - also supplies external muscles of the eyeball with motor and sensory fibers*
- 5th = *Trigeminal nerve - supplies muscles concerned with chewing and relays sensations from the face*
- 6th = *Abducent nerve - concerned with lateral eye movement and blinking*
- 7th = *Facial nerve - controls the muscles of facial expression, serves the taste buds on the front two-thirds of the tongue, and sensation to the skin of the fingers and toes*
- 8th = *Auditory nerve - concerned with hearing and balance*
- 9th = *Glossopharyngeal nerve - carries sensation and taste from the back of the tongue and throat; helps control swallowing*
- 10th = Vagus nerve - carries both sensory and motor connections to many organs in the chest and abdomen
- 11th = *Accessory nerve - supplies two neck muscles, the sternomastoid and the trapezius*
- 12th = *Hypoglossal nerve - supplies the muscles of the tongue and some of the small muscles of the neck*

RESOURCES

The Moebius Syndrome Foundation
P.O. Box 993
Larchmont, NY 10538
or call (914) 834-6008

Minnesota Moebius Syndrome Support Network

<moebius1@worldnet.att.net>

<<http://home.att.net/~moebius1/index.htm>>

Moebius Warriors International

Moebius1.org

PO BOX 169

Neshkoro, WI 54960

<<http://www.moebius1.org/>>

**Materials in Spanish for Families of
and Interventionists Serving Young Children
Who are Blind, Visually Impaired, and Deafblind**

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Working Together with Families and Children for a Brighter Future, September 1999

DB-LINK has a list of resources (articles, booklets, videos) in Spanish available for checkout. Call (800) 438- 9376 to request the list. The following papers can also be accessed on the DB-LINK website over the Internet in Spanish, <www.trwou.edu/dblink>, or write them for a copy.

- Communication Interactions: It Takes Two
- Early Interactions With Children Who Are Deafblind
- Expressive Communication: How Children Send Their Messages to You
- Overview of Deafblindness
- Psychological Evaluation of Children Who Are Deafblind
- Receptive Communication: How Children Understand Your Messages to Them
- Talking the Language of the Hand to the Hand

There are a couple of newsletters available in Spanish. First is *See/Hear News* (formerly *P.S. News*), published by Texas School for the Blind. This monthly newsletter contains articles for families and professionals on issues related to deafblindness and blindness with children from infancy to young adulthood. Many of the articles are available in Spanish on their website: <www.tsbvi.edu>. The second newsletter is *Resources*, published by California Deafblind Services. This quarterly newsletter has articles for families and professionals on issues related to deafblindness in children and youth. Their website is: <www.sfsu.edu/~cadbs>. Many fact

sheets (24) are also available from this agency on a variety of topics such as communication, light sensitivity, touch, CVI, otitis media, etc.

Vision Associates sells the two Tana Hoban baby board books, *Black on White (Negro en Blanco)* and *White on Black (Blanco en Negro)*. They have several titles of children's books available in Spanish which could be incorporated in a story bag or box with tactile objects connected with the story to use with children who are blind. Some of these titles are: *Margaret and Margarita*, *The Doorbell Rang*, *Lizard's Song*, *Ten/Nine/Eight*, *Chair for My Mother*, *Jump Frog Jump*, and *Something Special for Me*. They can be contacted at (407) 352-1200.

The Blind Children's Center in Los Angeles has several parent booklets available in Spanish. These include: *Talk to Me I and II*, *Let's Eat, Move with Me*, and *Selecting a Program*. Check out their website: <www.blindchildrenscenter.org> or call them at (800) 222-3566.

The following booklets and videos are also available in Spanish:

1. Video: *Building Blocks* on center-based preschool programming and the *Parent Early Childhood Education Series* are both available from American Foundation for the Blind, (800) 232-3044.
2. Videos: *Functional Vision Learning to Look and Learning to See* both on vision programming. The *Helping Your Child Learn Series* which provide information on teaching mealtime skills, dressing, choice-making, adaptations, and dealing with challenging behaviors. Contact BVD Promo Services for information: (800) 438-9832.
3. Video: *What Are You Trying To Tell Me?*, a video on early communication with children who are sensory impaired with additional disabilities, is available from the infant program of the Foundation for Junior Blind in Los Angeles, CA, (800) 352-2290.
4. Video and Book: The booklet on early orientation and mobility skills, *Pathways to Independence*, and video on adaptations in the preschool setting for preschoolers with vision loss, *A Special Start*, are available from the Lighthouse in New York City. Contact them at (800) 829-0500 or check out their website: <www.lighthouse.org>.
5. Video and Book: Deborah Chen's new project PLAI materials (video and print) on developing communication skills with infants who are deafblind and multidisabled will soon be available in Spanish from Paul H. Brookes, publisher.
6. Manual: *The HELP at Home Activity Guide* and HELP checklist are both now available in Spanish from VORT Corp. Contact them at (650) 322-8282.
7. *The Oregon Project Checklist* is available in Spanish from Jackson ESD, 101 North Grape Street, Medford, OR 97501, (541) 776-8580 or (541) 779-2018 (fax).

DBMAT and NFADB Update

By Patricia McCallum, Secretary of NFADB, Seagoville, TX

Summertime for Texans often means mowing the lawn more often, taking a well deserved family vacation, creating activities to keep our children busily happy, and relaxing in 70 degree air-conditioned environments. Summertime for the Members and Board of the Deaf-Blind Multihandicapped Association (DBMAT) means getting ready for our annual fall family conference!

Our Membership is gathering good used or new items from their other family members, their neighbors, co-workers, and local merchants to bring or send to our annual auction activities that are held during the conference. While they are doing that, the Board is working closely with our Conference Committee to plan all the particulars necessary to accomplish a successful fun-filled learning weekend for the families and professionals who will be in attendance.

The theme of our 28th Annual Family Conference is "Stepping Stones." It will be held over the weekend of October 13 -15, 2000 at Camp John Marc located near Meridian, Texas. DBMAT serves families of persons (children and adults) who are deafblind multihandicapped, deaf multihandicapped or blind multihandicapped and the professionals who work with them. Pre-registration is required. Registration and Child Vital Statistic Forms will be in our August Edition of our newsletter *In Touch*. For more information about DBMAT and our conference, call (972) 287-1904, e-mail <DBMATorg@aol.com>, or visit our website at <DBMAT.org>.

I also bring greetings from the National Family Association for Deaf-Blind (NFADB). NFADB is a non-profit, volunteer-based membership organization that is national in scope and advocates for all persons who are deafblind of any age and cognitive ability. NFADB's philosophy is that individuals who are deafblind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB is the largest national network of families focusing on issues surrounding deafblindness. We have eleven Regional Directors who serve as liaisons providing information, referral, and resources to families and professionals in their multi-state area. We work in collaboration with national projects such as DB-LINK, the National Technical Assistance Consortium (NTAC), the National Coalition on Deaf-Blindness and the American Association of the Deaf-Blind (AADB). NFADB publishes a tri-annual informative newsletter titled *News From Advocates for Deaf-Blind*.

For more information contact Debbie Ethridge (Arkansas), Region 6 Director, at (501) 271-8632 or Pat McCallum (Texas), Secretary, at (972) 287-1904 or e-mail <Pajomac@aol.com>. We invite you to visit our website <NFADB.org>.

United, We Stand

Terry Murphy, Executive Director, Texas Commission for the Blind

I've watched with interest over the years how words come in and out of vogue in the human services field. Some changes are easy to applaud, especially when the people most affected by the words seek and win the changes themselves. Because of the hard work by individuals and groups of Americans with varying disabilities, the term "handicapped" has given way to "disabled," and finally to "people with disabilities" in the Rehabilitation Act and other legislation during the last decade.

The latest target for change in this arena, however, does not have my support because the dissenting opinions of the individuals most affected by the proposal—people who are blind—have been ignored. The target I'm talking about is the goal by a few people and organizations to eliminate the word blind from the vocabulary of state legislatures and the U. S. Congress by calling for an end to its separate identity in laws and programs. Advocates for its elimination proffer their opinion that "people with disabilities" sufficiently says it all during human service funding and service debates. Recognition of the special needs of people who are blind is superfluous to the process.

Organizations of and for the blind have worked hard to educate legislators over the years to the unique barriers to employment and independent living posed by blindness because "existing services for people with disabilities" were not being made accessible to people who were blind. One important result of these education efforts is reflected in Title VII of the Rehabilitation Act. Entitled "Independent Living Services for Older Individuals Who are Blind," Chapter 2 provides funds to states to provide independent living skills to older individuals who are blind for whom significant visual impairment makes competitive employment extremely difficult to attain but for whom independent living goals are feasible. These funds, meager as they are, were celebrated across the nation and are used in Texas to prevent individuals from prematurely being relegated to nursing homes or caretakers when advancing age results in a loss of vision. With specialized training in adjusting to blindness, the majority of these individuals can remain in their homes and continue to be self-sufficient.

The Texas Commission for the Blind hosted a meeting a few months ago to talk about the future of vocational rehabilitation and independent living services, not only in Texas, but also across the country. In the room, the combined experience in the field of blindness numbered well into the hundreds of years. My colleagues and I shared our experiences, reflecting on the latest Texas legislative session when the specialized services provided by the Commission were being reviewed by the Sunset staff. The Commission entered the Sunset process confident in its record and proud that Texas chose the right path long ago when it created an agency with the sole purpose of building an effective system of services for individuals who were blind, including children and teenagers, which is rare in other states.

It was inconceivable to most of us that anyone would want to dismantle one of the best agencies for the blind in the country. Other states had gone that path only to be met with diminishing returns on their investment in services. Unfortunately we were wrong. It soon became evident during the legislative session that individuals and groups calling for an end to separately funded programs for people who are blind in Washington are also active in Texas. Their supporters were primarily advocating for serving people with all types of disabilities out of one Texas agency without having a separate budget for serving people who are blind. One advocate for change said that it is not necessarily accurate that individuals who are blind need that exact allocation of money, adding that agencies will always find a way to spend what they are given. The alternative of combining all human services programs into one elephantine agency with one budget also received some support.

Those of us who have chosen to work in the field of blindness as long as I have are so convinced that the elimination of distinct, separate services and funding would be detrimental that we have renewed our commitment to stay active in the coming months and years in educating the public, legislators, and congressmen about blindness and its unique effects on a person's ability to live and work. I simply do not believe that specialized services for persons who are blind of the same or better quality will be available in any service system where they are the small minority voice among persons with disabilities. It takes someone specially trained in the effects of blindness to be an effective service provider, and my 28 years in the field have only solidified my resolve to fight for the right of Texans struggling for equal acceptance into the world of employment to have dedicated resources for appropriate training and qualified state personnel with which to partner. The old saying, "United, we stand; divided, we fall" has taken on a very personal meaning to me on this particular issue, because cooperation between consumers and organizations of and for people who are blind over these next few years is extremely important.

I'm often asked by parents of children who are blind, "How can I keep up with what's happening? How can I make sure that people trained in the complications of blindness continue to be available for my child now and when he's trying to go into the workforce?" As an individual, you can be extremely effective by sharing what you know to be facts about blindness with your community and state leaders. You can join one of the consumer groups or parent groups that brings together people with the same needs and quest for knowledge about state and national activities that may have an effect—good or bad—on services for people who are blind. Stay involved even when things appear to be going well. Apathy can kill an endangered program just as effectively as the lobbyists already at work.

Congressional activities are already in motion in preparation for the reauthorization of the Rehabilitation Act in 2003. At this time, the Act is still a separate entity within the broader Workforce Investment Act. Vocational rehabilitation programs are only "linked" to local workforce programs—a "cooperative" arrangement. This federal change in 1997 is somewhat similar to state changes in 1999 when the Texas Commission for the Blind kept its separate

identity but now operates under the broad authority of the Health and Human Services Commissioner.

Two forces are alive and well at the national level: A force that continues to want work done by rehabilitation agencies merged or transferred into local workforce programs, and a force that wants to eliminate the states' authority to have separate rehabilitation programs for people who are blind. Either action will potentially eliminate the word "blind" from employment and independent living programs.

Programs for people who are blind were born in an era when leaders recognized that blindness was taking a toll on independence and employment that only specialized services could alleviate. Blindness still takes its toll. However, we have risen from that small beginning where the vast majority of blind people were expected to work in sheltered environments to today's multifaceted program of services where people can choose to pursue a broad range of careers that fits their interests and capabilities.

The people who know best the struggles of finding their rightful place in society are those who are themselves blind. Organizations composed of blind people have fought a valiant fight to have specialized services and will continue to do so as long as service providers listen to them and adjust to identified needs. Organizations composed of parents of blind children, including parents whose children have other disabilities in combination with blindness, have fought a valiant fight to have brighter futures for their children. Many years ago, the Commission was sometimes the object of these fights, but we began to better listen and respond. My personal goal for the past ten years has been to create an atmosphere wherein we stand together rather than stand separately.

If you are blind, if you have a loved one who is blind, or if you merely believe that blindness should not keep someone from participating in society to the highest extent possible, then I invite you to stand with us as we continue our efforts to educate others about the need for specialized services.

Information about Possible Changes in Texas Teacher Certification Requirements

Compiled by the Alliance of and for Visually Impaired Texans (AVIT)

BACKGROUND

In 1995, the Texas Legislature transferred from the Texas Education Agency (TEA) to the newly created State Board of Educator Certification (SBEC) all responsibilities related to establishing the requirements for teacher certification of Texas public school teachers. SBEC is currently reevaluating and changing the requirements for a number of Texas teaching certifications.

TEACHER CERTIFICATIONS FOR TEACHERS IN REGULAR EDUCATION

At this point, SBEC has approved three levels of teacher certification for regular educators:

- Early childhood to grade 4 which includes foundation subjects and enrichment areas such as art, PE, and music,
- Grade 5-8 which includes the foundation areas only, and
- Grade 8-12 certification. (A parallel bilingual certificate structure has also been proposed.)

SBEC PROPOSALS RELATED TO STUDENTS WITH VISUAL IMPAIRMENTS

SBEC has made the following three proposals related to certification requirements for teachers of students with visual impairments:

CERTIFICATION REQUIREMENTS FOR TEACHERS OF STUDENTS WITH VISUAL IMPAIRMENTS

Endorsement Currently Required.

Currently, teachers of students with visual impairments must have a teaching certificate plus an endorsement related to teaching these students. To obtain the endorsement, a teacher must pass coursework related to Braille, adaptations for low vision, anatomy, methods for teaching students with visual and multiple disabilities, and other specialized training in the areas unique to students with visual impairments.

Recommendation Will Eliminate Requirement for VI Endorsement.

In the fall, SBEC will recommend eliminating the endorsement for teachers of students with visual impairments thus eliminating the current requirement for these teachers to pass coursework related to Braille, adaptations for low vision, anatomy, methods for teaching students with visual and multiple disabilities, and other specialized training in the areas unique to students with visual impairments. SBEC will recommend one certificate for all teachers of students in special education, including students with visual impairments, and, as stated above, will not recommend an endorsement for teachers of students with visual impairments or any other special population.

SPECIAL EDUCATION CERTIFICATES AND UNDERGRADUATE EDUCATION

To support the new teaching certificates for regular educators, SBEC has increased requirements for each certification. For example, additional emphasis will be placed on reading for all three types of certifications. As a result of the increased coursework required for regular certification, including special education training as part of required undergraduate preparation might no longer be feasible. Special education training may be taken at the graduate level only. In Texas, we currently have one university offering an undergraduate program that includes specific training in the field of visual impairments—Stephen F Austin in Nacogdoches—and

another is being proposed by Texas Tech University in Lubbock.

CHANGES IN REQUIREMENTS FOR OBTAINING EMERGENCY CERTIFICATION

An emergency certificate is a teaching certificate that allows a teacher to teach in a particular area while the teacher completes particular requirements for a standard teaching certificate.

Initially, SBEC proposed eliminating the specialized emergency certification and replacing it with a 3-year certificate that would allow a teacher to teach in all teaching fields. The proposed requirements for the emergency certification included 1) a college degree of any type; and 2) the lack of a criminal history. Under this proposal, each school district would be required to develop training to support all emergency-certified teachers.

A newer proposal recommends:

- A Transitional Certification that includes 1) a special emergency certificate for special education and bilingual education; and 2) a requirement that the candidate must show progress toward certification; and
- A Transitional Certification for teaching students with visual impairments. The candidate for the certificate would be required to complete 6 semester hours related to teaching students with visual impairments and Braille competency but would not be required to possess a teaching certificate or have the support of a certified teacher of students with visual impairments as a teacher-mentor.

PROVIDING INPUT TO THE STATE BOARD OF EDUCATOR CERTIFICATION

Organizations and persons, including parents of children with visual impairments, may provide SBEC with information about teacher certifications in the following ways:

1. SBEC Website.

Persons and organizations may provide SBEC information about teacher certification requirements through its website (although the site is not uniformly accessible to blind consumers): <<http://www.sbec.state.tx.us>>.

2. SBEC Toll Free Number.

SBEC has the following toll free number for requesting and providing information related to teacher certification: 1-888-863-5880.

3. SBEC Information Contact.

SBEC employee Lennie Edwards may be contacted by email to request or provide information at the following email address: <ledwards@mail.sbec.state.tx.us>.

4. Attending SBEC Board Meetings.

SBEC will have meetings on November 3, 2000. Information on the Board's agenda is available at: <http://www.sbec.state.tx.us/geninfo/board_meet_agenda.htm>.

5. Correspondence by Mail.

Letters may be sent by mail to SBEC board members at the following address: State Board for Educator Certification, 1001 Trinity, Austin, Tx 78701 - 2603. Letters may be faxed to the following number: (512) 469-3002.

SBEC BOARD MEMBERS INCLUDE:

James D. Harris, Chair	Lubbock	Arthur Lacy	McKinney
Ed Patton, Vice Chair	Abilene	James B. Price	Cooper
Cynthia Tassos Phillips	Austin	Xavier Rodriguez	San Antonio
Mary E. Resendez	San Antonio	Kenneth R. Craycraft, Ph.D.	Huntsville
Antonio (Tony) Sanchez	Mission	Arturo Almendarez, Ph.D.	Texas
Mary Margaret Rucker	Nassau Bay	Education Agency	
Annette T. Griffin, Ph.D.,	Carrollton	William Sanford, Ph.D.	Higher
Keith Sockwell	Northwest ISD	Education Coordinating Board	
Carmel Borders	Austin		

Department of Education Issues Updated Policy Guidance on Educating Students Who Are Blind

Reprinted with permission from American Foundation for the Blind

The Department of Education, Office of Special Education and Rehabilitative Services has issued "Educating Blind and Visually Impaired Students; Policy Guidance" updated to reflect changes in the 1997 amendments to the Individuals with Disabilities Education Act. Below are a few highlights based on the major changes in the law that applies specifically to students who are blind or visually impaired.

ASSISTIVE TECHNOLOGY

- The consideration of assistive technology needs and the full range of devices and services that are available needs to occur as early as possible.
- If the IEP team determines that a child needs to use a school-purchased assistive technology device in the child's home or in other settings the device must be provided at no cost to the parents.

BRAILLE

- For a child to become proficient in Braille, systematic and regular instruction from knowledgeable and appropriately trained personnel is essential.
- IEP teams must ensure that the time allocated for Braille instruction is adequate to provide an appropriate level of instruction.
- An appropriate level of instruction must also be provided for children with low vision who utilize low vision aids.
- While Braille may be the reading medium of some students, the IEP team must consider methods for teaching writing and composition, including the appropriate use of assistive technology.
- As a supplement to Braille instruction, the IEP team must also consider what other skills a child might need to access information including the use of cassette recordings, personal computers with speech output or a Braille display, optical scanners with speech output, and reader services.

EDUCATION WITH NON-DISABLED PEERS

- The parents of the child must be members of any group that makes placement decisions.
- Placement decisions must be based on a child's IEP; making placement decisions before development of the IEP violate Part B of IDEA.
- The placement team must consider the full range of settings available appropriate in making placement determinations.
- Public agencies must make available a continuum of alternative placements or a range of placement options, to meet the needs of students for whom the regular classroom may not be the LRE placement.

O&M

- The Department recognizes the importance of O&M in participating in school and in an individual's eventual access to employment opportunities.
- Orientation and mobility services should be provided as early as possible in a child's education and updated and supplemented periodically as needed.
- Travel training should be considered for blind and visually impaired children, especially those with other disabilities, e.g., significant cognitive disabilities.

The full text of the policy guidance document can be found at <http://www.afb.org/grg/policy_2000.html> or <<http://ocfo.ed.gov/Fedreg/other/q200/060800a.txt>>.

Short Classes for School Year 2000-2001 at TSBVI

By Dr. Lauren Newton, Principal of Special Programs, TSBVI

This article describes the short classes offered at TSBVI during the coming school year. Short classes are **three to five days in length**. They provide **intensive instruction on a very specific skill related to vision impairment**. At this time, short classes are for students functioning at or near grade level. Referrals should be made through the local school district, so if you see a class that would be good for your child, talk to your VI teacher or special education director. Your child can participate in one or more programs during the school year. Students in five-day classes should bring their homework with them to complete during our supervised daily study hall.

PROGRAMS OFFERED

1. DISABILITY-SPECIFIC CLASSES WITH A PRE-DETERMINED CURRICULUM.

- Independent Living: Food Management & Personal Organization for ages 12-15.
Students attend four 3-day weekends:
 - September 14 - 17
 - October 27 - 30
 - January 12 - 15
 - February 16 - 19
- Technology Week (secondary students) has two separate programs, each one week in length:
 - October 15 - 20, 2000 for Braille 'n Speak/Braille Lite
 - February 25 - March 2, 2001 for JAWS for Internet
- Math Week (secondary students): April 1 - 6, 2001

2. ONE-WEEK INDIVIDUALIZED INSTRUCTION ON SPECIFIC IEP OBJECTIVES.

Students receive a week of one-on-one intensive instruction in any disability-specific IEP objective(s) jointly selected by the LEA and TSBVI.

High School Students

October 1 - 6, 2000
or
January 21 - 26, 2001

Middle School Students

November 5 - 10, 2000
or
February 4 - 9, 2001

Elementary School Students

December 3 - 8, 2000
or
March 18 - 23, 2001

HOW A SPECIAL PROGRAM CAN HELP

- Provides intensive instructional boost with only a short time away from home
- Teaches disability-specific skills that are pre-requisite to success in the regular classroom
- Provides individualized instruction to meet specific learning needs of academic students
- Provides temporary removal of multiple demands
- Addresses learning gaps caused by instructional overload
- Provides opportunity for professional collaboration regarding the individual needs of students

SHORT TIME AWAY FROM HOME

- Students bring local assignments (homework) to complete during tutored study halls
- All students return to local school at end of short program
- Participation in special programs is not a change in placement
- Students are not counted absent from their local schools
- LEAs support transportation costs

A TYPICAL DAY

During the school day, students focus on class content related to their IEP objectives. After school, they participate in Independent Living and Recreation/Leisure activities with other visually impaired students in TSBVI's carefully supervised residential setting. Tutored Study Halls are provided for week-long classes, during both the school and residential shifts, for students to work on assignments they bring with them from their local classes. Study Hall helps them keep up with classwork missed while at TSBVI. Secondary students attending the special classes also participate in a Teen Life class facilitated by a social worker, designed to let students share experiences with one another.

ABOUT SHORT PROGRAMS

There is growing national recognition that present educational models for serving visually impaired students may be incomplete. In particular, many students can succeed in their local schools if they receive a short, intensive instructional boost in certain disability-specific areas. These students do not need long-term services in a special classroom or school. But they can need intensive support during critical periods, which may be difficult to provide in the local school because of competing needs and limited resources. Residential schools for the visually impaired have the multidisciplinary expertise in the area of vision services to provide short, intensive classes for these students. The rationale for these programs is that a short time away

from the classroom at present will result in improved overall learning in the long run, because the students will be better able to benefit from future instruction.

During the 1999-2000 school year, TSBVI began offering a new kind of service delivery model: short-term programs. Classes were provided for academic-level students in the areas of Independent Living Skills and Technology, both fully attended and highly successful. This year we will expand our offerings significantly, with many short classes being offered throughout the school year. We will continue to offer the special classes. In addition we will offer a week of one-on-one intensive instruction in any disability-specific IEP objective(s) jointly selected by the LEA and TSBVI.

HOW TO REGISTER

Registration for short classes begins by contacting a TSBVI Special Programs' staff member (see contacts below). At that time, we will talk together about the student and the program. If there is a mutual decision to continue the process, formal registration procedures will be described and initiated. Students must apply for any short class no later than 8 weeks before the program begins. In order to provide good ratios class sizes are limited. Eligible students will be admitted in the order in which they apply.

MORE INFORMATION

If you work with a student who may benefit from any of these programs, or if you would like to share or receive additional information, please contact:

Dr. Lauren Newton, Principal of Special Programs
(512) 206-9119
email: <LaurenNewton@tsbvi.edu>

Jeri Cleveland, Lead Teacher for Special Programs
(512) 206-9346
email: <JeriCleveland@tsbvi.edu>

CLASSIFIED

Mail or e-mail your new classifieds to Jim Durkel at:
TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or <jimdurkel@tsbvi.edu>.
An up-to-date Statewide Staff Development Calendar
is posted on TSBVI's website at <www.tsbvi.edu>.

Future Horizons

A weekend workshop for families
of children with
visual impairments (6-9 years old)
September 22-24, 2000
Galveston, Texas

For further information contact:
Jeannie Mojica-LaCrosse
(512) 206-9268

The Deaf-Blind Multihandicapped
Association of Texas (DBMAT)
presents the
28th Annual Family Conference
"Stepping Stones"

October 13 -15, 2000
at Camp John Marc
located near Meridian, Texas

This conference is for families of persons who are deafblind multihandicapped, deaf multihandicapped or blind multihandicapped and the professionals who work with them.

Pre-registration is required. Registration and Child Vital Statistic Forms. For more information about DBMAT and our conference, call (972) 287-1904, or e-mail <DBMATorg@aol.com>, or visit our website at <DBMAT.org>.

Make your plans now to attend the **2001 Texas Symposium on Deafblindness**

at the Radisson Hotel Central Dallas
February 15 - 17, 2001

This conference will offer a variety of state and national speakers focusing on various issues in the field of deafblindness.

Registration flyers will be sent to SEE/HEAR recipients in the Fall of 2000. For more information or to add names to the mailing list contact Beth Rees at (512) 206-9103.

Second Annual Sports Extravaganza for Blind & Visually Impaired Students **October 13 & 14, 2000** **Nimitz High School, Irving, TX**

Students who are visually impaired and blind ages birth-22 years old will have the opportunity to participate in a variety of adapted sports activities including baby and parent obstacle course, wheelchair obstacle course, goal and beep ball, archery, shot putt, 25-100 meter dashes, long jumps, and softball throw. Parents, PE teachers, and adapted PE teachers are encouraged to attend with their student(s).

For more information contact: Kitra Hill Gray (972) 348-1580 or Randy Foederer (972) 348-1570.

INSITE:

A Home-Based Model for Infants, Toddlers, and Preschoolers Who Are Sensory Impaired With Other Disabilities

This six-day training is for professionals who work with these children and their families. If you are interested in attending this training or bringing this training to your area, please contact Gigi Newton at (512) 206-9272 or email her at <GigiNewton@tsbvi.edu>.

Trainings have already been scheduled in these locations:

San Angelo, Texas

Part I

September 25-27, 2000

Part II

October 23-25, 2000

Contact: Debbie Louder
at (915) 658-6571

Houston, Texas

Part I

November 8-10, 2000

Part II

Jan. 30-31 & Feb. 1, 2001

Contact: Jake Peno
at (713) 744-6378

Putting the Pieces Together for Students with Severe Disabilities Effective Teaching Strategies for Children with Severe Disabilities

This training will focus on effective teaching strategies which meet the needs of people who work with students with severe and profound disabilities and will provide a framework for implementing innovative programs. The participants will develop an action plan to facilitate the steps needed to maximize the potential for children with severe disabilities. Target Audiences: Teams of school personnel and the family.

Training Locations and Dates:

September 26-27, 2000

Amarillo: Region 16 ESC

Contact: Stormetta Stateler
(806) 376-5521

October 17-18, 2000

Midland: Region 18 ESC

Contact: Lu Cleere
(912) 563-2380

November 15-16, 2000

Huntsville: Region 6 ESC

Contact: Nodya Thornton (409) 435-2195

December 5-6, 2000

Edinburg: Region 1 ESC

Contact: Peter Graves
(956) 984-6165

For more information call the Low Incidence Disability Project at ESC Reg. 3 Phone (361) 573-0731 or email <sdavis@esc3.net> or <msscott@esc3.net>

REGIONAL WORKSHOPS

September 22, 2000

Setting Curricular Priorities for Students with Visual Impairments

Location: Region X ESC, Richardson, TX
Presenters: Amanda Hall Lueck from San Francisco State University
Contact: Kitra Hill Gray (972) 348-1580

December 14-16, 2000

The Arc of Texas and Region 20 ESC Present The 8TH Annual Inclusion Works! Conference: Diversity Shines

Location: San Antonio, TX
Contact: (800) 252-9729
or <www.thearcoftexas.org>

January 24, 2001

Gathering Information and Programming for Students with Visual Impairments and Profound Disabilities

Location: Region X ESC, Richardson, TX
Presenters: Jenny Lace and Robbie Blaha,
Texas Deafblind Outreach
Contact: Kitra Hill Gray (972) 348-1580

January 25, 2001

Meeting the Unique Needs of Students with Hearing and Visual Impairments

Location: Region X ESC, Richardson, TX
Presenters: Jenny Lace and Robbie Blaha,
Texas Deafblind Outreach
Contact: Kitra Hill Gray (972) 348-1580

March 28, 2001

How Do Adult Rehabilitation Agencies Assist People with Visual Impairments: Criss Cole and Lions World Rehabilitation Centers

Location: Region X ESC, Richardson, TX
Contact: Kitra Hill Gray (972) 348-1580

Spanish-Speaking Parents of Children with Visual Impairments

TSBVI Outreach has a Spanish-Speaking Parent Network for parents of children with visual impairments. If you want to join this network, get the name of another Spanish-speaking parent you can contact for support and information, or want articles and information in Spanish, please contact Jean Robinson at (512) 206-9418 or email <JeanRobinson@tsbvi.edu>.

SEE/HEAR is published quarterly: February, May, August, and November. Contributions to the newsletter are always welcome. Articles can be mailed or e-mailed to section editors at:

**TSBVI Outreach
1100 West 45th St.
Austin, TX 78756**

Family - Jean Robinson
(512) 206-9418
<JeanRobinson@tsbvi.edu>

Programming - Ann Rash and Gigi Newton
(512) 206-9269;
<AnnRash@tsbvi.edu>
(512) 206-9272;
<GigiNewton@tsbvi.edu>

Syndromes/Conditions - Kate Moss
(512) 206-9224;
<KateMoss@tsbvi.edu>

News & Views - Jim Durkel
(512) 206-9270; <JimDurkel@tsbvi.edu>

Deadlines for articles are:

December 1st for the Winter edition

March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

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**SEE/HEAR is available in Spanish and English on TSBVI's website at
<www.tsbvi.edu>.**

If you no longer wish to receive this newsletter,
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Family and Professional Training Needs Survey

- Parent/Family Member
- Professional

1. What training have you and/or your family (excluding your child with disabilities) had the OPPORTUNITY to participate in during 1999-2000?

- family retreats
- local/regional workshops
- statewide conferences (list: _____)
- national conferences (list: _____)
- information from the Internet
- information from printed materials such as newsletters, articles, books etc.
- parent/family support groups
- individual consultation at home by (circle those that apply: local school staff, regional vi staff, TSBVI Outreach)
- individual consultation at school by (circle those that apply: local school staff, regional vi staff, TSBVI Outreach)
- chatrooms/listservs
- email
- other: _____

2. Of the training opportunities you had available, which ones did you take advantage of during 1999-2000?

- family retreats
- local/regional workshops
- statewide conferences (list: _____)
- national conferences (list: _____)
- information from the Internet
- information from printed materials such as newsletters, articles, books etc.
- parent/family support groups
- individual consultation at home by (circle those that apply: local school staff, regional vi staff, TSBVI Outreach)
- individual consultation at school by (circle those that apply: local school staff, regional vi staff, TSBVI Outreach)
- chatrooms/listservs
- email
- other: _____

3. What topics do you need more information about?

- Advocacy, for example

- Special education law, for example

- Disability, for example

- Educational programming issues, for example

- Independent living, for example

- Impact of disability on my family,for example

- Sexuality issues, for example

- Medical issues, for example

- Technology issues, for example

- Resources, for example

4. What formats for training do you prefer?

- Face-to-face workshops locally or regionally
- Distance education workshops
(e.g. videoconferencing, web-based)
- Large state or national conferences
- Family retreats
- Internet information
- Videotapes
- Articles to read
- Newsletters
- Support groups
- Informational fairs/exhibits
- Individual consultation at home
- Individual consultation at school
- Chat rooms/listservs
- Email
- Other?

5. What obstacles do you face in getting training or information?

- Time away from my family
- Release time from work
- Cost of travel to training
- Cost of registration
- Child Care while in training
- Computer/Internet access
- Access to videotape/audiotape/
DVD player
- Location too far away
- Times that training is offered
- Length of training
- Language barriers
- Topics of training
- Awareness of when/where training is
being offered
- Other

6. Thinking about the issues you checked in #5, what would make access to training and information more accessible for you?

7. Other comments about training?

8. Regarding SEE/HEAR newsletter, what articles or types of articles have you found particularly helpful?

9. What kinds of articles or what topics would you like to see included in SEE/HEAR?

10. Would you be willing to write an article for SEE/HEAR or do you have an idea for an article you would like to see written? If so, what would it be about? How can we contact you?

11. If you could make one change to SEE/HEAR, what would that change be?

12. If you are currently receiving SEE/HEAR in a format other than regular print English, do you have comments about the quality or need for these additional formats?

Completed Surveys should be mailed to:

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