

# 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

It's ironic how events occur. For the past several weeks I have been busy revising materials for the "Through Your Child's Eyes" workshop. This workshop was developed about ten years ago by Dr. Dixie Mercer and Sue Currey, who at that time worked with VI Outreach. It has been a gift to many Texas families in the early part of their journeys toward understanding their child's disability. I had the privilege of working with Dixie, Sue, and Sue's husband, Jim Currey, when the focus of the workshop was expanded to include families of children with deafblindness. Although others of the Outreach team got involved in different aspects of the workshop when Dixie left Outreach and Sue took a disability retirement, it was always Sue's and Dixie's creation. Sue was very proud of it.

Last week we learned that Sue had passed away. After years of overcoming illness brought on by diabetes, she was gone. Sue was one of the most courageous people I've ever known, though I doubt she would have described herself that way. She just kept fighting back because she loved her life and her husband. She taught me a lot about living with a visually impairment, but she taught me more about life. We shared a love of children and a deep respect for families. She was a friend. I would like to dedicate this edition of SEE/HEAR to her memory.

## Dreams, Plans and Self-Determination

By Craig Axelrod, Teacher Trainer, TSBVI, Texas Deafblind Outreach,  
with Edwin Carter, Teen, Dallas, TX and Rosie Yanez, Mentor, El Paso, TX

A seminar entitled "Self-Determination: Creating a Path to the Future" sponsored by the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC), took place in Columbus, Ohio on July 29 – August 4, 2000. It was held in conjunction with the 25<sup>th</sup> Anniversary Conference of the American Association of the Deaf-Blind (AADB). The conference was attended by approximately 350 people who are deafblind, as well as 650 interpreters, support service providers (SSPs), conference facilitators, presenters, and interested observers.

At the seminar, a group of 21 deafblind teens/young adults and young adult mentors from 9 states explored such questions as: What does self-determina-

tion mean to me? How have deafblind adults become self-determined about their lives? How can I become more self-determined about my own life? What interests, dreams and challenges do I share with other deafblind teens and young adults? What does it mean to be a mentor?

Several three-person teams participated in the training. Each team included a teen/young adult, mentor and state deafblind project representative. Edwin Carter (teen/young adult) from Dallas, Rosie Yanez (mentor) from El Paso and I represented Texas. Teams that were selected agreed to attend the seminar, develop an Action Plan to support the teen/young adult in becoming more self-determined, then maintain contact for a year and participate in follow-up activities using e-mail and/or the Internet.

## WHAT IS SELF-DETERMINATION?

Brian Abery, from the University of Minnesota, defined self-determination to the group as “Living the way I want to live instead of how others expect me to live,” and “Taking the amount of control over your life you want, in the areas you want to control.” There are many short term and long term decisions that people make to control their lives. Most people don’t want to be in total control of every part of their lives, but may want to share control with family, friends, and others. Letting someone else take control of certain things, however, might mean accepting responsibility for other things. Giving up control may also require compromise. For example, letting someone else cook the meals might mean you have to do the dishes or take out the garbage, and you may also have to eat foods that are not your favorites.

Having control over decisions feels good, but may also be scary sometimes because it means accepting responsibility for decisions that might not turn out well. It can be frustrating and depressing, though, for other people to make all the decisions, even with the best intentions. Everyone needs opportunities to make decisions for themselves, even if that might mean making mistakes.

**Craig:** What are some things in your life that you want to control?

**Edwin:** I already have independence in the dorm, and I control management of my time. I want to have more control about traveling in Austin and other places.

**Rosie:** I want to be assertive and not have to depend on other people. I

must stand up for myself. I don't want to fail in college because of poor services. I can't control what services are provided or offered, but I can advocate for what I think I need. I also want to have better control of my temper because my own attitudes will influence how other people respond to me. I want to be an advocate for other people with Usher Syndrome.

## WHAT DO I NEED TO BECOME SELF-DETERMINED?

Maricar Marquez, from Helen Keller National Center (HKNC) in New York emphasized that, in order to be self-determined, it's important to have the necessary skills, knowledge, attitudes/beliefs and supports. Susie Morgan, with NTAC, noted that skills in areas such as communication, independent living, orientation and mobility, decision making, self-advocacy and self-regulation are essential. Knowledge of rights and responsibilities, educational options, resources and systems, and society (on a local, national and global scale) are also important. A self-determined person's attitudes and beliefs are indicated by a positive outlook on life, self-confidence, high self-esteem, a sense of determination, and internal control. Supports can originate in different places. For example, family members and close friends might offer emotional support. Communication support might come from support service providers (SSPs), interpreters or interveners. Access to technology and enhanced physical accommodations might provide the necessary educational support. People who want to become self-determined about something must identify the skills, knowledge, attitudes/beliefs and supports they already have, and those they need.

Following Maricar's presentation, a panel of deafblind adults was introduced. Each adult gave a brief autobiography to the group, then individual panel members met with the teams from different states. They talked about the skills, knowledge, attitudes/beliefs and supports they have and those they are still developing or acquiring.

**Craig:** What skills, knowledge, attitudes/beliefs or supports do you have to be self-determined? What do you need?

**Edwin:** I need to learn to stop waiting and do things *now*.

**Rosie:** I have the skills to speak up for what I believe in, but I also need to be around other deafblind people who understand and support me. At AADB people weren't focusing on my Usher Syndrome or my vision and hearing prob-

lems. I could be myself. I need role models who are good self-advocates and mentors. That will also help me be a good mentor for Edwin.

## HOW CAN I PLAN FOR THE FUTURE?

Jerry Petroff and Cindy Ruetsch, from the New Jersey Technical Assistance Project, guided teens in the group through a step-by-step process that included dreaming about “What I can be,” to determine which parts of those dreams are realistic and figure out how to reach them. When dreaming about the future it’s important to think big. Without dreams a person isn’t motivated to move ahead and may not know in which direction to move. Visions move people closer to their dreams, within a time frame of five to ten years. To help clarify a vision someone can say, “In order to reach my dream, I must/should/can...,” then ask, “Is my vision positive? Is my vision possible?” If both questions can be answered “Yes,” the next step is to identify three goals related to the vision. These goals are smaller pieces of the vision that can be accomplished within a year. It’s also important to know what people and supports or resources are necessary or can be helpful in completing those goals. Three “next steps” related to each goal are then selected to be achieved in one or two months.

After Jerry and Cindy’s explanation of a step in the planning process, each three-person team met to help its teen develop that step. By day’s end, the teens all had Action Plans of goals and specific steps to complete within the coming year that will help them move toward their individual dreams and visions.

**Craig:** What is one of your dreams and your vision to reach it? What goals and “next steps” will you accomplish to move closer toward that vision and dream?

**Edwin:** I want to own my own technical or computer business, but first I’ll need to attend a technical college. I graduate from TSD (Texas School for the Deaf) next May and plan to start college the following fall. I’m getting Bs in my high school classes now, and I’ve already received application information from two colleges.

**Rosie:** I want to share my experience and be a teacher with deafblind children. I can make a big difference. I’m going to college now for my degree. In the next year I want to improve the interpreter program at my community college for myself and for other students who are deafblind. I’ll need to identify the issues first, and then start looking for solutions.

## WHAT IS A MENTOR?

Mentors are essential members of the three-person teams. All of the mentors at the seminar participated in additional training, to learn what being a mentor means and to discuss ways that mentors can help teens/young adults achieve their dreams.

Mentors draw from their own experience and share it with others who find themselves in similar situations. Mentors give empathy, support and understanding. Mentors are trustworthy advisors who do not judge others as right or wrong, but remain open to different perspectives and beliefs. Mentors may not be able to solve other people's problems, but they are good listeners who offer suggestions and ideas. Mentors also help others become good self-advocates who are knowledgeable about issues and their rights.

**Craig:** Rosie, what does being a mentor mean to you?

**Rosie:** I want to be someone Edwin can look up to like a big sister... to answer questions, give advice and help him feel good about himself. We can help each other.

**Craig:** How will you help Edwin continue to make progress toward his dreams?

**Rosie:** Not to bug him, but to keep in touch and become a valuable person in his life.

**Craig:** Edwin, in what ways is Rosie a good mentor?

**Edwin:** Her experience will help me a lot as I plan my future. We work as a team.

**Rosie:** I remember my first experience with a deafblind adult. A long time ago Kim Powers came to El Paso. My Mom was driving Kim to the airport and signing in her hand. Kim was so happy. I was sitting in the back seat watching and thought if she can be happy, so can I. You can be happy or sad, but happiness is possible.

## COMMUNITIES & CONNECTIONS

While seminar participants attended daily training sessions about self-deter-

mination, time was also set aside for tours and other more informal get-togethers. These occasions provided opportunities to become better acquainted with each other, as well as to meet, work, and relax with deafblind adults. The deafblind adults attending this conference were impressive role models for living self-determined lives.

By the end of their week together, teens and mentors had developed and strengthened relationships among themselves and realized that they are members of a larger deafblind community. While planning gets underway for the next national AADB Conference in 2003, discussion has also begun about creating an affiliated organization of and for deafblind teens/young adults. Participants of this year's seminar on self-determination may become the nucleus of a planning committee for a teen/young adult component at the 2003 Conference.

**Craig:** What did you enjoy most about the Conference?

**Edwin:** I met many interesting deafblind adults.

**Rosie:** I enjoyed meeting other deafblind teens and mentors and sharing experiences with them.

**Craig:** Will you continue your involvement with other participants from the Seminar?

**Edwin:** I'm doing a lot in school (homework, football, work, etc.), but I want to stay involved.

**Rosie:** Yes. I already got e-mail from Andria in Oregon and Theresa in California.

**Craig:** What can we do to organize deafblind teens/young adults in Texas?

**Edwin:** Start a support group in Texas for teens and young adults. Join AADB.

**Rosie:** Keep in touch. Find places where teens can use computers. Get an eCircle going. Raise money every year for a fun trip together.

As a participant in NTAC's "Self-Determination" Seminar and as a first time

attendee of an AADB Conference, I was profoundly impressed by the high level of energy, commitment, mutual support, optimism and information offered by everyone there. I strongly encourage deafblind teens and young adults in Texas to meet each other at a local, regional, and state level. They should also consider becoming involved with a national organization such as AADB.

*Editor's note: If you are interested in self-determination for deafblind teens and young adults, contact Rosie at [roseyaney@hotmail.com](mailto:roseyaney@hotmail.com), or Edwin at [TheBull16@juno.com](mailto:TheBull16@juno.com). Edwin and Rosie will be speaking about self-determination at the statewide Deafblind Symposium in Dallas, February 16-17, 2001. Mark your calendars.*

## **Ten Reasons to Introduce Blind Role Models to Families**

By Jean Robinson, Family Support Specialist, TSBVI, VI Outreach

During my ten or so years of working with families I have found that children cannot effectively make progress in isolation; they come with parents. Parents can be a teacher's or administrator's best advocate or worst nightmare. Either way they cannot and should not be ignored. Often I have heard comments about parents like these: "They always want more." "They are never satisfied." "They always complain." "They don't 'get it.'" "They don't see the big picture." Too many times I feel parents are patronized when they express their concerns or ask questions.

Professionals in the small field of vision impairments are immersed in the world of blindness. They tend to forget sometimes that parents don't know the basics. Most parents have little, if any, experience with blindness. Often they are too scared to think about their child becoming an adult. But these parents are just like us. We all need dreams, even unrealistic ones, to motivate and challenge us each day. I'm sure I am not the only parent who told her children they could be rocket scientists. I have also been known to buy a lottery ticket or two, even though the odds of winning are ridiculous. Parents of a child with a disability become short-circuited when they cannot nurture dreams in their own lives, dreams that include the lives of their children.

A practical, informative way to help parents build dreams for their child's

future is to connect them with blind mentors or role models. Our last “Future Horizons Family Gathering” gave over seventy parents an opportunity to ask basic questions about living with a visual impairment. It also helped them to begin to look into the future of their child with joy and expectation instead of fear. The mentors were solicited from Texas Commission for the Blind caseworkers and counselors, vision teachers, and also from consumer groups (National Federation of the Blind Texas, American Council of the Blind Texas, Texas Federation of the Blind). The mentors varied in ages (14 years and older) and background. Students with visual impairments, along with their siblings, were able to spend individual time with a variety of mentors. In some cases, it was the first time they ever meet another person with a visual impairment. That alone was a powerful experience.

The parents also spent both informal and structured time talking with mentors. Two mentors sat at each of five tables while the parents rotated to each table to discuss a variety of topics related to living with blindness and visual impairments. Topics of discussion included daily living skills, educational experiences, employment issues, social skills, as well as orientation and mobility skills and transportation issues. The mentors were asked to share their experiences, both good and bad. Of course these topics overlapped some, but they gave a focus and starting place to the discussions. Parents spent fifteen minutes at each table learning how an individual lives his or her life with blindness or visual impairments. Although the group was too large to share a lot of information in such a limited time, parents had the chance to meet all the mentors and hear a variety of experiences. The families made an initial connection with mentors and can keep in touch as they need to in the future. This activity was a great success.

So what are the ten reasons to introduce blind mentors or role models to families? The reasons are evident in the families’ comments:

1. “I learned that children should still be children and be treated as normal as possible.”
2. “My outlook has become more positive after listening to and speaking with the mentors. I’d previously thought assisted living would be the only option for my son, and I realize now the only future that is completely closed to him is the one he doesn’t try.”
3. “I was very much inspired by the mentors and by seeing the success of other students with visual impairments.”

4. "I realized that there really are no limits. It's a matter of getting my child the exposure he needs to be able to have many options."
5. "I enjoyed talking with the teens about social situations and independence. They calmed my fears about social interaction. I also learned a great deal about the value of incidental learning."
6. "The best part of the weekend was being able to talk to other people who are having similar problems and find out how they are handling them."
7. "I learned that kids with visual impairments can be successful... college graduates and business owners."
8. "Now I believe my child can be anything she wants, and more."
9. "The best part was meeting other parents and mentors and gaining support and information."

Do these comments surprise you? They are the feelings that most parents want to have about their children with visual impairments. These parents do "get it" now. They heard real stories from real people living every day with blindness and visual impairments. The whole weekend was an uplifting experience for everyone. The mentors enjoyed meeting the families and sharing their stories as much as the families enjoyed listening and questioning.

By the way, I didn't forget the tenth reason.

10. Parent training is included in the law (See IDEA 300.24(b)(7)). Related services not only include things like orientation and mobility, physical therapy, occupational therapy and the like, but may also include recreational opportunities and parent training. State special education funds may be used for training of parents (300.382(j)).

Obviously, there are more than ten reasons to introduce families to blind mentors or role models. Many of you could add several more reasons to this list. Those of you who have regional family events please spread the word about the mutual benefits of involving mentors. Enlist a family member to write about their experience and take the opportunity to brag in this newsletter. These family/mentor events are worth doing. They promote partnerships between parents, professionals, and blind and visually impaired leaders in the community. They also give students a chance to understand the need for and to develop and practice lifelong skills that lead to independence.

## Victoria's Eyes

By Rene Gonzalez, Father, Kyle, Texas

On December 17, 1997, Victoria Loreen Gonzalez was born at 8:00 a.m. She was a beautiful baby full of life. During Victoria's first year she had spent a week in the hospital due to a urinary tract infection. She also had regular well-checks and visits to the doctor for immunization and sick visits. For us it was twelve months of happiness and total delight in our daughter.

When she turned fifteen months old, she had a seizure caused by high fever. Three different baby doctors checked her. All of the doctors agreed that a simple rash had caused her temperature to rise quickly. Each doctor checked her eyes and other parts of her body for any abnormalities and assured us there were none.

Time passed and Victoria was having the typical experiences of a child. We could see her strength and courage as she attempted to walk. Very soon she was getting into every part of our home. She played with others, and she enjoyed the outdoors.

At about 20 months we took Victoria to the doctor for a wellness check. At that time we complained about her sleeping problems. She had begun to have sleeping problems and would cry. We would try to comfort her and relieve her distress, but nothing helped. Her pediatrician suggested her problems with sleeping were due to bad dreams or gas.

Not long after that visit I spotted a strange metal-like reflection in her left eye. I asked others in our family if they saw the same cloud. Immediately I felt a need to cover her right eye. She refused to allow the right eye to be covered. I tried poking her left eye to observe her reaction. Her left eye stayed open as if she did not have any fear of being touched. Immediately we scheduled an appointment with the doctor.

As we waited in the doctor's office, Victoria played and enjoyed herself. This time the doctor thoroughly checked her eyes; she turned off the light and closed the mini-blinds. I told the doctor that an object was only visible when Victoria's eyes were looking upward. The doctor started the procedure, then immediately rose from her seat and left the room. We were left alone, and a very cold silence fell around us as we stared into her precious little face.

The doctor returned with instructions for us to go to an ophthalmologist. It was 5:45 p.m. on a Friday, and we were in the south part of Austin. Dr. Busse, the ophthalmologist we were referred to, had his office on the other side of town, about 45 minutes away in the heavy Friday rush-hour traffic. Before we left our pediatrician, we were only able to gather that she saw a growth in Victoria's eye. We found out later that in her many years of practice, she had never diagnosed a child with this type of growth.

That drive from her office to Dr. Busse's began a journey of pain and suffering for both Victoria and us. The day seemed to go into a kind of slow motion. We sensed that a deep fissure had been opened in our life. The possibilities of what the doctor meant by "a growth" ran on a loop in our minds. The worst fear parents can have, that of something harming their child, was becoming a reality for us.

Once we entered Dr. Busse's office, he immediately dilated Victoria's eyes three times. Victoria was beginning to show an impatience for all this new testing on her eyes. Suddenly we both noticed a large white globe in Victoria's left eye and smaller globes in her right eye. Dr. Busse stood up and left the room in haste. He returned with a handout and a box of tissue. He sat down and gave us the tissue box. He told us Victoria has cancer in both of her eyes, and we must work fast to save her.

We were thrown once again into that loop of emotions, struggling with fear and sadness. At first I held strong trying to support my wife who at that moment was in total distress. Then I soon joined her in my own fear and sadness. Victoria was beginning to worry, and she became saddened by our reactions. We held her tight. We were so unsure what her future would be. We were faced with a huge decision to make and no time to ponder the options.

Dr. Busse gave us the basics. The cancer Victoria had is called retinoblastoma. He told us that this form of cancer is very rare, very aggressive, and can be life threatening. He stated that the hospitals in Houston were very experienced in treating this form of cancer and that we must decide whether or not to begin treatment immediately. He also gave us a second option and that was to begin the early test here in Austin. The decision was difficult for us. We had to decide what was the best treatment for Victoria. We decided to stay in Austin because we had family and friends here while in Houston we knew no one. Dr. Busse made the arrangements with the children's hospital, and moments later we were on the road again heading into the unknown.

As we traveled to the hospital with tears rolling down our faces, I felt like stopping the car, getting out, and screaming. I wanted to shout until everyone could hear, "My beautiful 22-month-old baby has cancer!" I knew, staring at the other cars as they passed by, that the people inside them had problems and troubles of their own. Still I felt that no child should have to endure such pain and suffering, especially not my beautiful daughter. How could my young baby girl have such a destructive disease?

Now we entered the hospital, a place that would soon become our second home. We passed by the chapel, and we also passed by several other cancer patients. The first procedure they did on Victoria required an IV-line to be inserted into my baby's little veins. Victoria's blood had to be drawn continuously to monitor her red blood cell count. It took both of her parents, three nurses and a support board to hold Victoria down. As I held Victoria's head I stared into her lifeless left eye, and I could see the white growth in there. My tears were now mixing with Victoria's. Her pleas for help went unanswered, for we knew this was only the beginning.

It was now 11:00 p.m. Friday evening, and Victoria was being prepped for a series of X-rays. Once again she had to be held down by a support board underneath a huge X-ray machine. I could not imagine what Victoria felt, but as she pleaded for help, I knew she was asking why, and what had she done wrong? This procedure lasted an hour and then we were on another ride, this time to another hospital for an MRI. The MRI was required to make sure the cancer had not spread to the rest of her body.

The only break Victoria had was that she was put under because the test required complete stillness. The loud beat of the machine did not help the cold silence. By 3:00 a.m. we were heading back to the first hospital. It seemed that the darkness of the night was no match to the darkness that had fallen on Victoria and on us.

The next day began at 6:00 a.m. with more blood work and an early visit from Dr. Busse. He gave us some good news. The cancer was mainly engulfed within the eyeballs. Therefore complete removal of the eye would prevent any growth of cancer into the brain. Dr. Busse informed us that he was not a specialist in retinoblastoma, but that he had enlisted the services of another Austin doctor, Dr. Harper, who deals with this type of cancer. Then Dr. Shore entered, who specializes in the removal of eyes and optic nerves, and implants. He was very professional and answered every question we had about the dan-

gers of removing the eye. He doubted it was possible to save her eyesight.

By 8:00 a.m. both doctors had given us their opinion. Then the geneticist visited and questioned us about our family history. This information would help determine if the disease was genetic or just an unfortunate twist of fate. The genetic testing is also required for tracking the disease and to alert us to the possibility of cancer developing in our other child or within our families. Conclusive results from this testing would take several months. Before the next doctor entered, we were completely exhausted, emotionally drained, and hopeless. Our daughter who had only seen a fraction of the world was now on the edge of being in complete darkness. There is no way I can describe our states of mind at this moment. We both so desperately felt we needed help.

In a sense the next two doctors could be called miracle workers. Dr. Harper is a retina specialist, and Dr. Lockhart is an oncologist. Dr. Harper looked in Victoria's eyes and studied them as best he could. He said that the left eye would have to be removed because it was full of tumor, and Victoria had no vision in that eye. It would be safer to remove the eye and eliminate the possibility of metastasis. Dr. Harper then went on to explain that he could save Victoria's vision in her right eye. He said it with such confidence that we were at his mercy. Let me tell you, because of Dr. Harper's confidence, some of the sorrow and heartache was lifted from our hearts. (Thank you Dr. Harper.)

Dr. Harper and Dr. Lockhart, armed with their research, told us they believed a nine-week series of chemotherapy would help slow the cancer down. That therapy, combined with using a laser and freezing, might let Dr. Harper save the right eye. They agreed that the left eye had to be removed immediately.

It was now noon and we were back on a roller coaster of emotions, trying to make the best decision for our daughter. We knew the options. If she kept the left eye there was a stronger possibility the cancer would spread. Keeping the right eye also added to that risk. Still the whole idea of placing Victoria in complete darkness in just two days was too much to bear. On the other hand losing her altogether was our worst nightmare. After 48 hours without sleep, our bodies were showing the strain. During the night I entered into the chapel and prayed for the forgiveness of our sins and also for guidance and strength.

Once they did the eye exam under anesthesia, Dr. Shore and Dr. Harper concluded that the tumor was so big in the left eye that it had enlarged the eye. That meant that the removal of the eye would cause severe pain, and a long

healing process would be necessary before they could begin chemotherapy. That also meant the tumors on the right eye could continue to grow.

At 5:00 p.m. Monday evening Dr. Harper called us with a new twist. He had been doing a lot of research about new aggressive treatments for retinoblastoma and had called doctors all around the world to find out what new techniques they were using on this type of cancer. He had found another option for us. We could remove the eye now and wait for the chemotherapy or start chemotherapy now and removal the eye later. He felt that the best chance for Victoria was to start chemotherapy immediately and try to keep some of her sight. He went on to explain that chemotherapy would be the only way to slow the growth of the tumors on the right eye and would also shrink the inflamed tumor on her left eye. By 7:00 p.m. Monday, Victoria's first wave of chemotherapy began, and by 9:00 a.m. Tuesday her first series of laser work had also begun. After a week of blood draws, X-rays, MRI scans and surgery to attach a portocatheter to Victoria's chest, we went home.

By the end of October the physical demands of the chemotherapy were showing their effects on Victoria. She had lost a good portion of her straight light-brown hair. She had also lost five pounds. Two more laser and freezing treatments had been conducted. Also the first wave of chemotherapy had ended. She had no appetite, and she was very weak. Her immune system had caused her to continuously have a cold and a never-ending rash.

Financially we were having a hard time, so we had to remove both children from day care. Luckily, my wife Judith's parents never left our side. If not for them our jobs, our faith, and our hope would have been washed away.

November brought in the second wave of chemotherapy and another series of work on Victoria's eyes. By Thanksgiving her health had weakened more and all of her hair had fallen out. She now had a slight case of pneumonia and a herpes-like rash. Since she was receiving chemotherapy, there was very little antibiotics would do to help. The day before Thanksgiving the fever broke and the rash had cleared slightly. Victoria was rebounding. Before her last chemotherapy treatment her blood count had lowered to near the danger point, so she now required a blood transfusion. Her blood count had to improve before the final round of chemotherapy could be administered. I thank those people who give blood to help her because the change was immediate.

By the end of the chemotherapy treatment she had gained weight and was

back to enjoying just being a child. The rash and cold were still present, however, and again she experienced another fever seizure. The lost look in Victoria's eyes and the lack of strength in her body frightened us into believing that she would truly be lost.

Yet eventually she stood up, and then there was no stopping her. She would celebrate her 2-year-old birthday, a day we thought would never be celebrated. With the help of family and friends, she once again would feel normal. Her life could be more than doctors and nurses. Soon she would also experience the ending of a century and the beginning of a new millennium.

The beginning of the year came along with the day we had dreaded. Victoria's left eye would be removed on January 11, 2000. After four hours of surgery, we waited two more hours for her to open her only remaining eye. When she awoke she was only troubled by the stitches that held her left eye shut. Otherwise, she went through surgery with a lot of courage. Several weeks later the stitches were removed and the prosthesis was inserted.

Every three weeks from October 1999 through October 2000, Dr. Harper has been working on Victoria's eye. Victoria's health is still weak. She often gets colds and rashes, but she plays like any other child. By October 2, 2000, after a year of lows and highs, our journey has led us to a straightway. The three tumors on her eye are in remission and are no longer growing. Although this does not end her torture, it does give strong support to her future.

This story I have written began with strong and powerful emotions. It has been very hard for me to write about it, recalling all the things we have been through. It took me several days just to get down what happened that first day when she was diagnosed. As tears ran down my face and on to the page, it seemed that first day was happening again. For you see, we lost our first child six years prior to Victoria's diagnosis. It took us three years before we could think about having another child. Like a miracle, our first child was born six years into our marriage and we named him Elijah Jacob. When Victoria was born our family was complete. But when Victoria's cancer was diagnosed, all the old emotions of our first lost child returned. The only difference was that with Victoria we had a chance to fight for her life. Luckily for us, Victoria's will and courage would not let her give in to this destructive disease.

The final thing I can say is that Victoria's loss was our gain. She lost her eye, but she gained love, hope, and faith from strangers, friends, doctors, and nurses.

Both my wife and I would like to encourage doctors in Texas to regularly use special screening procedures to help detect the presence of eye conditions such as retinoblastoma in infants and toddlers. In California there is currently legislation being considered that would change eye-screening protocols for children under the age of two. One of the main components of the new protocol is to dilate the eye for early examination, a very inexpensive procedure.

Retinoblastoma is a childhood cancer and accounts for approximately 13% of all cancers in infants. Most children are diagnosed before two and one-half years of age. When retinoblastoma affects both eyes, the average age of diagnosis is 12 months. An abnormal screening will facilitate timely referral to an appropriately licensed health care provider and to an ophthalmologist for treatment.

Early detection and referral of an abnormal red reflex pupillary screening would allow early diagnosis of congenital cataract or retinoblastoma which, if recognized and treated as soon as possible after birth, could reduce long-term disability. Early diagnosis and intervention might also reduce the number of visually impaired citizens. It could also cut down on the public's expenditures for health care, special education, and related services. Spending a little money early in the life of a baby could save so much in terms of dollars, but also in the pain and suffering of children and their families. We need to make sure children in Texas have the best health care possible. This protocol could save sight and lives.

## **The Patience of Justin**

By Cheri Scott, Parent and Family Specialist  
Alaska Dual Sensory Impairment Services

My husband Allan and I are parents of three kids: Heather Amy, who is 27 and has no apparent disabilities, Daniel, who is 22 with Attention Deficit Hyperactivity Disorder and Learning Disabilities, and Justin, who is 13 and has Fetal Alcohol Syndrome, Cerebral Palsy, Mental Retardation, Dual Sensory Impairment, and Seizure Disorder.

Justin came into our lives as a foster baby when he was 5 months old. He'd been born at 26 weeks gestation weighing 2 lbs., 2 oz. and with a blood alcohol level over twice the legal limit for driving while intoxicated. It took him four days

to “dry out” cold turkey. He had many complications during his 3 months in the Neonatal Intensive Care Unit (NICU) at Providence including a detached right retina, damage to the left retina, a grade 3 bleed that left him with significant brain damage, respiratory and cardiac problems and, at times, uncontrollable seizures. When he came to live with us we were told that he would probably not be a long-term survivor. If by chance he did live, he would be almost completely blind, able to see only light and dark contrast. Justin would need full-body support since he’d never be able to sit or stand by himself, and he would require round-the-clock care.

There was no huge miracle that made him a perfectly developed typical boy. But for those of us lucky enough to be part of his life, we know that there have been countless small miracles built out of the hard work, faith, and perseverance of many loving, dedicated people over the last thirteen years. The greatest credit goes to Justin for his patience, sweet disposition and positive nature. He waits for the rest of us to understand what needs to be done. He accepts our fumbling and mistakes as we search for the best ways to help him reach his potential.

Currently, Justin is in 8th grade in an intensive needs classroom with aide-supported participation in regular education elective classes. He walks with forearm crutches, uses sign language, a small amount of speech, and an electronic voice output device to communicate. He reads at a 1st-to-2nd-grade level and loves books. He wears hearing aids, with the addition of a wireless FM system when at school, and glasses to see anything farther than four feet away. He takes medication to keep his seizures under control and to reduce the spasticity in his legs. He also wears plastic orthotic braces on his feet and lower legs to help him walk and stand comfortably.

Last year was busier than usual for Justin. He was selected as the Children’s Miracle Network (CMN) Champion for Alaska. He represented Alaskan kids served by the Children’s Hospital at Providence at fund-raisers around the Anchorage community throughout the spring. In June, Justin took my husband, Allan, our other son, Dan, and me to Washington D.C. and Disney World for the National CMN Telethon. Justin’s favorite part of the whole trip was Disney World’s Blizzard Beach, where we spent the steamy hot day floating on inner tubes around and around the perimeter of the park. Other highlights included meeting Mickey Mouse, riding in a little jet boat with his big brother, and the electric light parade in Fantasyland ( three times!).

Hadley School for the Blind selected one of Justin's original pictures for their Christmas card this year, the first time it has used a student's artwork. The card is being sold to help the school raise money to fund the correspondence programs it provides free of charge to individuals with vision impairment and their families. Willard Scott showed the card on the Today Show, and according to the folks at the school the demand for cards was very good.

We're very proud of our son and all the great things he's been able to do in his life – with a little help from his friends.

Our family's experience with Special Education Service Agency's (SESA) Alaska Dual Sensory Impairment Services began about two-and-one-half years ago when our son's hearing loss was confirmed at ten years of age. After years of incomplete hearing tests from audiologists untrained to work with children experiencing developmental and physical disabilities, I took to heart the words of the physician I work with, Dr. Brennan, and took Justin to experts. Three separate testing days confirmed our worst fears. After years of attributing his lack of speech to his other disabilities (Cerebral Palsy from a severe brain bleed at two weeks, following his premature birth at 26 weeks gestation, and Fetal Alcohol Syndrome, Mental Retardation and Epilepsy), we were devastated by the diagnosis.

I remember returning my son to his school and crying as I tried to share the audiologist's report. As we talked, Laura Metcalf, Justin's resource teacher, made the comment that his visual impairment may have been a blessing in disguise. To insure Justin could see our expressions we had always tried to stand close to him when speaking, using sign language as well, because he didn't seem to be picking up speech. Without the diagnosis of a hearing impairment we had no signing support from the school district. Each year, to the best of our own meager ability, we had to educate the new staff on communication techniques to use when working with him. We have been very lucky to have supportive team members willing to follow our lead throughout most of Justin's school career.

We were very late in receiving Justin's diagnosis of hearing impairment. No one can tell us how long he has had difficulty hearing. Recent studies noting the high percentage of hearing and vision problems in children with FAS, however, lead us to believe that he has probably been hearing impaired since birth. It is thought that this high percentage of hearing and vision loss is related to the anatomical differences caused when the cells of the developing fetus come

into contact with alcohol during the 19th-21st days of gestation. This is the time when the structures that will become eyes, internal ear structures, upper palate and other mid-face features are forming.

Speech therapists, physical therapists and occupational therapists have been some of our most important team members. Many of the professionals working with our family have had some training in FAS and have a general understanding of how children can be affected by prenatal alcohol exposure. As Justin's main advocates, it is our job to make sure they remember that each child with this disorder is unique and to keep reminding them of the specific ways our son is affected.

Justin has a short attention span. Even when he is intensely interested in what is being presented, lights, movement and sounds from the surrounding area can easily distract him. Leg tremors related to his cerebral palsy can do the same thing.

Justin has sensory and tactile defensiveness. For him this means he is sensitive to loud noise and busy visual environments. His response to too much sensory stimulation ranges from hysterical laughter progressing to tears, staring at bright lights and shaking his hand in front of his good eye, humming snatches of song over and over, or retreating to a quiet dark space like a darkened bathroom, bedroom or laundry room.

Justin is an experiential learner. To understand new things, he has to see, feel, hear and taste them. Abstract concepts are far beyond his understanding. If you say "See you later," he expects you to come visit before bedtime. "Wait a minute," means that when the seconds on his digital watch get to :00 it will be his turn.

Justin has a processing delay. That means that after he reads, and especially after he hears new information, it takes time for his brain to understand the information and decide how to respond. This can take up to 20 seconds if a question is long or complex. It may seem to the person interacting with Justin that he is ignoring them or choosing not to respond to their question. This delay in responding may also be interpreted as a problem behavior.

To compound things, people will quite often repeat or reframe their question, thinking that he didn't hear or understand them the first time they spoke. When that happens, Justin's mind shifts to the new statement and starts from the

beginning again, like punching a button on the CD player to go back to the beginning of the song.

For years, school staff members were frustrated when Justin seemed to shut down during conversation attempts. Yet he had no other way of dealing with the unending demands of conversations that he couldn't understand or respond to quickly. So he would resort to his favorite word, "NO," or flap his hand in front of his eye and gaze at the lights in the classroom. As Justin has matured and begun to gain a sense of control over his world, he has learned to use the pointy-finger-to-lips "SHHHHH" sign and sound when he's feeling like too much information is coming too fast.

Justin is a wonderful boy with a sweet, patient temperament. He's also at high risk for being victimized. To Justin the term "friend" means anyone that makes eye contact, smiles or talks to him. Because of his vision, hearing and motor difficulties, as well as his lack of understanding of dangerous situations, he needs constant supervision when out in public. Things like making sure he's aware of curbs and sidewalk edges that could catch his crutch tips, navigating icy sidewalks, high snow berms, and traffic and dealing with loose dogs or predatory people need to be taken into account.

As Justin matures, we (Justin and his family) will continue to be faced with challenges brought on by his disabilities. Still, we are definitely a part of our community, and Justin has many people who care about him. With his continued patience and the support of these community members, we feel optimistic that his life will be rich and full. We know that our lives are certainly richer and fuller for having him.

*Editor's note: I met Cheri Scott this summer while I was in Minnesota attending the Hilton/Perkins-NTAC sponsored workshops on Family Issues. During lunch one day, Cheri asked how many students were on the Texas Deafblind Census with an etiology of Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE). FAE is a lesser set of the same symptoms which make up FAS. Babies affected by alcohol can have any or all of these symptoms. FAS and FAE are widely under-diagnosed. Some experts believe that between one-third and two-thirds of all special education children have been irreversibly affected by alcohol in some way. At least 5,000 infants are born each year with FAS; another 50,000 children show symptoms of FAE.*

*As I talked more with Cheri about this etiology, I realized how important it*

is for us to be aware of children whose vision and hearing problems may be caused by this syndrome. These children are exceptionally hyper-sensitive or hypo-sensitive to sensory input. As a result, they may be likely to shut down in noisy or visually busy environments, or be very upset by sensory stimulation activities. When we are assessing these children's hearing and vision, especially functional assessments, we may not get responses quickly because of processing and response problems. It would be natural to assume they didn't see or hear the test item, when in fact they might have. Inconclusive or inaccurate testing of their senses may be a real possibility if these factors aren't taken into consideration. Hearing loss for these children can be sensorineural, conductive, a processing disorder, or combination of all three. They may also have vestibular problems that affect balance.

Luckily, these children do benefit from many of the same instructional strategies and modifications that work for the child with deafblindness or visual impairment and developmental disabilities. Using instructional routines, teaching choice-making skills, and structured social skills development can help. Making adaptations for vision and hearing issues such as avoiding glare and bright lights, using appropriate assistive listening devices such as FM systems, having appropriate glasses, using color to add visual recognition, and so forth, can also be important. However, we need to carefully monitor the child's responses, talk to his caregivers (the real experts on his responses/needs), and assess, plan, and work together as a team to make sure the individual child's needs are being appropriately addressed.

Many of these children will not grow up in their birth parents' homes. Often, they may be raised in foster homes or with extended family members. It is our responsibility to make sure these caregivers have the information and support they need as well.

Children with Fetal Alcohol Syndrome have some very unique needs. As you will see in the article "Understanding Issues with Fetal Alcohol Syndrome" by Blanche Stetler, there are some tried and true approaches that should be used with these kids. It is also important to note that some children with Fetal Alcohol Syndrome will not be diagnosed or identified as such. That makes our task as professionals serving these children and their caregivers all the more difficult.

By the way, in Texas we have not identified any children with Fetal Alco-

*hol Syndrome on the 2000 Deafblind Census. Are we failing to identify these children as having FAS, or are we not identifying them as visually impaired or deafblind because of their other disabilities?*

## **Fetal Alcohol Syndrome**

By Blanche Stetler, Parent and Family Specialist  
New Jersey Deafblind Project

In September of 1989 we adopted a little boy who we named Timmy. Timmy was 2 weeks old at the time, and, unbeknownst to us, was born to a mother who both drank and took drugs while she was pregnant. We found this out during a regular office visit to our pediatrician after our doctor had received Timmy's birth records from the adoption agency. Since then, we have been on a roller coaster ride between doctors, therapists, and educational professionals trying to get him the help he needs. Tim has both a vision and hearing impairment caused by Fetal Alcohol Syndrome. He also has Attention Deficit Hyperactivity Disorder (ADHD) and a Seizure Disorder. Even though he is now 11, developmentally he is at 5-6 year-old level. We have tried many different medications over the years to control his hyperactivity and seizures. It is an ongoing battle. It seems whenever he has a growth spurt, the medications no longer work, and we go on to something else.

Even though we knew Timmy's birth history when we started visiting neurologists, it still took many years for us to get a firm diagnosis of Fetal Alcohol Syndrome (FAS). We have compiled the following information over the years to help us. Some things were from doctors and others were from teachers, therapists, professionals, books, and support groups.

### **CHARACTERISTICS OF FETAL ALCOHOL SYNDROME**

Fetal Alcohol Syndrome is diagnosed when children meet the following criteria:

1. Growth deficiency, prenatal or postnatal, for weight, length or both.
2. A specific pattern of minor anomalies that includes a characteristic face, generally defined as small eye slits, a flat mid-face, a short upturned nose, a smooth or long philtrum (the ridges running between the nose and the lips) and a thin upper lip.

- 3. Some neurological damage, including small brain size, tremors, hyperactivity, fine or gross motor problems, attention deficits, learning disabilities, intellectual or cognitive delays, hearing or vision deficiencies.
- 4. A diagnosis of FAS also requires some presumed history of prenatal alcohol exposure.

Many FAS children:

- Have difficulty structuring work time.
- Show impaired rates of learning.
- Experience poor memory.
- Have trouble generalizing behaviors and information.
- Act impulsively.
- Exhibit reduced attention span or are distractible.
- Display fearlessness and are unresponsive to verbal cautions.
- Demonstrate poor social judgment.
- Cannot handle money age-appropriately.
- Have trouble internalizing modeled behaviors.
- May have differences in sensory awareness (hypo- or hyper-).
- Show poor problem solving strategies.

Children with FAS also have an increased occurrence of other physical problems that can be traced to their prenatal alcohol exposure, and can contribute to their overall disability. Additional eye anomalies can include ptosis (drooping eyelid), strabismus (deviation of the eye), and myopia (nearsightedness), as well as underdevelopment of the optic nerve, twisted retinal vessels and blindness. The high occurrence of hearing disorders in children with FAS is associated with alcohol induced developmental delays. Types of hearing loss may include sensorineural hearing loss and central auditory processing disorders associated with abnormalities of the brain stem. Misshapen secondary teeth are also common in these children.

**EFFECTIVE STRATEGIES FOR HELPING THE FAS CHILD**

- Foster independence in self-help and play.

- Give your child choices and encourage decision-making.
- Focus on teaching daily living skills.
- Avoid situations where your child will be over-stimulated.
- Have your child get ready for the next school day before going to bed.
- Establish routines so your child can predict upcoming events.
- Give your child lots of advance warning when a planned or usual activity is going to change to a different activity.
- Break your child's work down into small pieces so he/she does not feel overwhelmed.
- Set limits and follow them consistently.

## RESOURCES TO LEARN MORE ABOUT FAS

It is always a safe bet to begin your information search for any syndrome or condition with Family Village. For their listing on FAS go to <[http://www.familyvillage.wisc.edu/lib\\_fas.htm](http://www.familyvillage.wisc.edu/lib_fas.htm)>. Here are three excellent resources listed at Family Village:

National Organization on Fetal Alcohol Syndrome  
 216 G Street North East  
 Washington, DC 20002  
 Phone: (202) 785-4585; Fax: (202) 466-6456  
 E-mail: [information@nofas.org](mailto:information@nofas.org)  
 Website: <[www.nofas.org](http://www.nofas.org)>

This is an excellent website for a variety of articles on FAS, including teaching strategies, tips for parents and much more.

Fetal Alcohol Education Program (FAEP)  
 Boston University School of Medicine  
 1975 Main Street  
 Concord, MA 01742  
 Phone: (978) 369-7713; Fax: (978) 287-4993

The Fetal Alcohol Education Program is dedicated to research and education for the prevention, identification and treatment of alcohol-related

neurodevelopmental disorders. Among their materials available for sale are two teaching packages, one for education professionals entitled *Alcohol, Drugs, and the Fetus: A Teaching Package* (84 slides, a 65-page manual) and *Here's to Healthy Babies* for the education of parents and community groups (call or write for details). They have also developed a handbook for parents, *FAS: Parent and Child* (\$7.50 per single copy; bulk rates available), and make a reprint list available.

Family Empowerment Network: Supporting Families affected by FAS/FAE  
 610 Langdon Street, Room 523  
 Madison, WI 53703-1195  
 Phone: (800) 462-5254 or (608) 262-6590;  
 Fax: (608) 265-2329  
 E-mail: fen@mail.dcs.wisc.edu

Family Empowerment Network (FEN): Supporting Families Affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects is an international organization serving families and professionals. They provide: free informational packets on FAS/FAE; international resource/referral directory catalogued by state/province; quarterly newsletter, *The FEN Pen*; extensive loan library (videos, audio training tapes, books, fact sheets, etc.); trainings for parents and professionals; educational opportunities; an annual retreat for families; and an annual national conference. FEN is a program of the University of Wisconsin-Madison, Department of Professional Development and Applied Studies.

Some other nice resources suggested by Cheri Scott include:

*Fetal Alcohol Syndrome: A Guide for Families and Communities.* Steissguth, Ann Ph.D. (1997). Published by Paul H. Brookes Publishing Co; (800) 638-3775; Stock No. 2835; Cost: \$22.95.

Fetal alcohol syndrome: craniofacial and central nervous system manifestations. *American Journal of Medical Genetics* 61:329-339, 1996.

*Fetal alcohol syndrome and fetal alcohol effects*, produced by Fronske Health Center, Northern Arizona University for the NAU website. Go to <<http://www.nau.edu/~fronske/fas.html>>.

Fetal alcohol syndrome, from the *Roots and Wings Adoption Magazine*. Available on the Roots and Wings website at <<http://www.adopting.org/rwfas.html>>.

Fundus morphology assessed by digital image analysis in children with fetal alcohol syndrome. Hellstrom, Ann, Chen, Yahua, and Stromland, Kerstin. *Journal of Pediatric Ophthalmology and Strabismus*, January/February 1997, Vol. 34, No. 1.

Hearing, speech, language, and vestibular disorders in the fetal alcohol syndrome: a literature review. Church, Michael W. and Kaltenback, James A. *Alcoholism: Clinical and Experimental Research*, Vol. 21, No. 3, May 1997.

## What is Fetal Alcohol Syndrome?

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National Organization on Fetal Alcohol Syndrome (NOFAS)  
website <<http://www.nofas.org/what.htm>>

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) refer to a group of physical and mental birth defects resulting from a woman's drinking alcohol during pregnancy. FAS is the leading known cause of mental retardation. Other symptoms can include organ dysfunction, growth deficiencies before and after birth, central nervous dysfunction resulting in learning disabilities and lower IQ, and physical malformities in the face and cranial areas. In addition, children may experience behavioral and mental problems, which progress into adulthood.

- FAE is a lesser set of the same symptoms, which make up FAS. Babies affected by alcohol can have any or all of these symptoms. FAS and FAE are widely under-diagnosed. Some experts believe that between 1/3 and 2/3 of all special education children have been irreversibly affected by alcohol in some way.
- No amount of alcohol consumption during pregnancy is known to be safe.
- FAS is the leading known cause of mental retardation, surpassing both Spina Bifida and Down's Syndrome. (*Journal of the American Medical Association*, 1991)
- At least one of every five pregnant women uses alcohol and/or other drugs. (*Substance Abuse and the American Woman*, Center on Addiction and Substance Abuse, Columbia University, June 5, 1996)

- Alcohol produces by far the most serious neurobehavioral effects in the fetus when compared to other drugs including heroin, cocaine and marijuana. Annual cost estimates for FAS and related conditions in the United States range from \$75 million to \$9.7 billion. (*Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment*, Institute of Medicine, 1996)
- The Centers for Disease Control and Prevention reported a sixfold increase in the percentage of babies born with FAS over the past fifteen years. Since the Centers began tracking FAS, the rate has increased from 1 case per 10,000 live births in 1979 to 6.7 cases per 10,000 live births in 1993. (*The New York Times*, April 7, 1995)
- Over three times as many women used alcohol during pregnancy than used illegal drugs. (National Institute on Drug Abuse, 1994)
- Each year more than 5,000 are born with FAS and nearly 50,000 babies are born with Fetal Alcohol Effects (FAE), a condition characterized by symptoms similar to but less severe than FAS. (*Public Health Education Information Sheet*, March of Dimes, 1992)
- Fewer than 57% of Americans under the age of 45 have even heard of FAS. Of those, less than 25% can correctly identify it as a set of birth defects while the rest think it means being born intoxicated or addicted to alcohol. (*National Health Interview Survey*, U.S. Department of Health and Human Services, 1985)
- An average of one to two reported drinks per day has been linked to decreased birth-weight, growth abnormalities and behavioral problems. (*Alcohol Problems in Women*, 1984)
- The probability of having a child with FAS increases with the amount and frequency of alcohol consumed. Whenever a pregnant woman stops drinking, she reduces the risk of having a baby with FAS. (*Alcohol Health and Research World*, The National Institute on Alcohol Abuse and Alcoholism, 1995)
- The latest estimate for the U.S. is a rate of 19.5 per 10,000 live births, although estimates run as high as 30 per 10,000 - about 12,000 babies a year. (*Substance Abuse and the American Woman*, Center on Addiction and Substance Abuse, Columbia University, June 5, 1996)
- A 100% misdiagnosis rate was reported in a Houston hospital study of 48 newborns known to have alcoholic mothers. By age one, 6 of the

infants had significant signs of FAS but none had been diagnosed at birth. (Little, Bertis, Snell, Laura, 1990)

- A federally funded study in four U.S. Southern communities found that only 65% of women were asked by a physician or nurse about alcohol or drug use during their most recent pregnancy. Further, although most of the women who were asked acknowledged substance abuse, only 3% were referred to treatment. (Shelly Geshan, Southern Regional Project on Infant Mortality, 1993)
- A national panel convened by the Josiah Macy Jr. Foundation found that most doctors do not even try to identify problems by asking patients questions about alcohol and drug habits, and do not know how to respond if they do find evidence of dependency. The panel called for an increase in mandatory training on substance abuse for medical residents as the first step toward improving treatment. (*The New York Times*, February 14, 1996)
- A National Center for Health Statistics study found that doctors appear less likely to tell black women to quit drinking and smoking during pregnancy than they are to tell white women. Pregnant black women were 30% more likely than white women to report that they had never been told to quit drinking, and 20% more likely to report that they had not been told to quit smoking. (*The New York Times*, January 19, 1994)

## **It's Almost Time for the 2001 Texas Deafblind Census**

This is a reminder to parents and professionals about the 2001 Texas Deafblind Census. Each year in Texas and around the country all school-aged children with combined vision and hearing loss are included on a special registry, the Federal Deafblind Census. This information is used to identify both the numbers and needs of children in this country who have unique educational issues resulting from combined vision and hearing loss or deafblindness. It also plays a role in determining grant funds that each state receives to help these children, their families and the professionals working with them. In Texas, these funds flow through the Texas Education Agency to Texas Deafblind Outreach and the Texas Deafblind Census. The funds help families, professionals and paraprofessionals attend workshops and conferences, support the production costs of *SEE/HEAR*, and many other things. A child with a mild vision loss and/or a mild hearing loss may be eligible for inclusion in this count. While

the census is compiled only once a year, children may be added to the census at any time. If you know of children who should be added on the Census, begin the process to get them on there now. For help in determining if your student is eligible, contact your ESC Deafblind Specialist, the Texas Deafblind Census, or Texas Deafblind Outreach. Parents, if you are not sure if your child should be listed on the census, ask your school IEP team to check with these resources.

## **Disabled Find Many Barriers Online**

By Andrew Park, Staff Reporter, Austin American Statesman

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Tired of having to squint to read the display of his small green computer screen, Guido Corona one day replaced it with a 19-inch television. When text on the edges blurred beyond recognition, he pulled a cardboard box over his head and the monitor to block out extraneous light. When light seeped in anyway, he lined the makeshift hood with black paper to cover the cracks. When he found himself squinting again, he rigged his computer to talk to him and sound-proofed his office so colleagues wouldn't be bothered by the noise.

It was 1984 and Corona, a programmer in the research labs of IBM Corporation, was losing his eyesight to retinitis pigmentosa, a degenerative disorder that can lay dormant for half a lifetime and then turn a sighted person blind within a matter of months. Elsewhere within IBM, blind programmers were rigging printers with rubber bands and coat hangers to get them to print Braille and going back to primitive punch card sorters that could be read by their hands. They knew - even in the early days of the personal computer - that a technological revolution was coming and they didn't want to be left behind.

Today, PCs can be custom-made for the visually impaired, and a whole industry has grown up to develop technologies to help people with disabilities. But that doesn't always make them useful to folks like Guido Corona, because much of the Internet - which has become so important in American life that it increasingly separates the haves from the have-nots - remains inaccessible to people with disabilities. They struggle every day to find their way through complex Web pages that are clogged with animation, video and data that would fill

reams of paper but are void of any accommodation for their needs.

Ten years after the passage of the Americans with Disabilities Act, which forced corporations and governments to address the needs of people with disabilities in the physical world, advocates are focusing attention on the barriers in the virtual world. It is another digital divide, and if you think the issue is simply the ability to shop online, think again. At some point, the Internet will be the platform for learning, working and participating in society. Texas is pushing hard to adopt electronic textbooks in public schools, for example, but they will be of little value if students with disabilities cannot use them.

“To the extent that the world is moving to the Internet, it ups the ante that we have to be there or we cease being competitive,” says Curtis Chong, director of technology for the National Federation of the Blind in Washington. “We’ve always said that blind people can be competitive. But being competitive can be tough to do if the technology is moving too fast for you to keep up with.”

## **FIGHTING FOR ACCESS**

According to a study released in March by researchers at the University of California-San Francisco, less than 10 percent of people with disabilities regularly use the Internet, versus nearly forty percent of people with no disabilities.

In the past two years, major computer and software makers have decreed that their products will be built with accessibility for everyone in mind, from people who can’t use a mouse to those who can’t hear the computer’s beeps and whistles. But the needs of people with disabilities still get trampled under the rush to expand the Internet and use it to transform all aspects of American life, from business to government to education.

“Ninety percent of the Internet pages have some problem with accessibility,” says Kelly Ford, a Portland, Ore., consultant who teaches web design to corporations and is one of the more outspoken advocates of building accessibility. “Inaccessible information is just as much a barrier as a set of steps is to a person in a wheelchair.”

After years of pushing technology companies behind the scenes to improve the accessibility of their products, the fight is becoming public. In the past year, advocates for people with visual impairments have sued major corporations including Bank of America, H&R Block and Intuit, claiming the companies’

popular software and Web sites aren't compatible with the screen-reading technology they use to surf the Web. They charged that Internet services such as online shopping, banking and tax preparation constitute public accommodations that, under the ADA, have to be as accessible to people with disabilities as the public library or the mall.

America Online recently settled a suit by agreeing to make future versions of its Internet service software accessible to screen readers and other technology that people with disabilities use. The Department of Justice ruled in 1996 that the ADA applied to the Internet, and the government is adopting rules requiring accessibility in all technology it buys. The rules are expected to encourage state and local governments as well as the private sector to pay more attention to the issue.

But it remains to be seen whether corporate policies and government regulations can keep up with the explosive growth of the Internet. New elements are added every day to Websites, often without regard to how different viewers might experience them. The emergence of affordable high-bandwidth connections such as cable modems and DSL has encouraged Web designers to create sites with complex features like streaming audio and video, animation and built-in, executable programs – elements that even many people without disabilities have trouble using.

“I think as the Web continues to grow, it gets more inaccessible,” says Jim Allan, information technology director at the Texas School for the Blind and Visually Impaired.

With the advent of each new potentially world-changing Internet application --- telecommuting, distance learning, online voting, digital signatures, e-books --- people with disabilities question whether they will be able to take advantage, too.

“Every new thing that comes along, the first thing that I do is worry,” Chong says, “I will say that most of my worry has been justified.”

## **SCREEN-READER SUCCESS**

Guido Corona is not alone at IBM, and was not when he joined in the early 1980s. Long before the Web existed, computing's emphasis on the visual caused problems with blindness and other disabilities, forcing them to improvise. Each time such improvisations failed him, Corona cursed his state-of-the-

art computer and blamed technology, even though he knew it was his vision that was reaching obsolescence.

“It was me, my eyes that were going the way of the Edsel or dodos,” says Corona, 47, his eyes hidden by mirrored sunglasses more suited to a Texas state trooper than a computer programmer.

As he continued to struggle, Corona learned that an IBM researcher named James Thatcher was developing a program that, when combined with a speech synthesizer, could read text aloud from a PC screen.

“That was really a very important thing for the blind community, because it opened up jobs that wouldn’t be available to them,” says Thatcher, who retired from IBM in April.

Corona jumped at the chance to be one of the early testers of the product – called PC-SAID – beginning a long association with Thatcher that culminated in 1996, when IBM moved its Special Needs System group, which was charged with bringing all of the company’s efforts in developing computing for people with disabilities, to Austin. Corona, then working in Toronto, soon followed. By the early 1990’s, millions of people were logging onto e-mail and a text-based Internet through services such as AOL and Prodigy, including many blind people who used screen-reading programs. With the invention of the Web browser, though, developers were able to format text into boxes and columns and add logos, charts, photographs, and drawings and the Internet began to evolve into a much more graphic environment.

Once again, people with disabilities were left behind. Not only did the emphasis on spectacular graphics mean that visually impaired people using screen readers were stymied; the growing emphasis on the mouse as a tool for navigating the visual world of the Internet also meant that many people with mobility problems would be left out.

“In 1997, I was essentially refusing to recognize it because it was truly becoming a schizophrenic experience,” Corona says. “There were less and less places that you could go to.”

About the same time in a laboratory in Tokyo, an IBM researcher was programming a screen reader that would recognize not just conventional text, but also the tags in HTML that control where text is displayed, its appearance and

its function on Web pages. The program, called Home Page Reader, offered the visually impaired user signals to how a Web page was laid out and how to navigate it. Thatcher's group brought the software to the United States and released a second version last year.

Home Page Reader - and programs like it from assistive-technology companies such as Henter-Joyce Inc. - rely on web developers to include text alternatives to graphic elements as they are programming their pages. It is an easy step in designing a page, but one many programmers overlook.

"When the issue of accessibility comes up, that's not the number one priority. The number one priority is to have a nice-looking product," says Adam Weinroth, a Web developer at Mediatruck Inc. in Austin, whose team won first place in a contest last fall in which local design firms created accessible Web sites for nonprofit organizations. "Now it's to the point where people are potentially missing out on customers or missing out on revenue because of it."

Indeed, people with disabilities are increasingly looked upon by corporations as a lucrative market, and their combined buying power of \$300 billion is only expected to grow as baby boomers age.

But change is not easy. Advocates bring inaccessible sites to the attention of the companies that run them, and their recent targets have been some of the biggest names on the Web: Dell Computer, Citibank, Priceline. After becoming a faithful customer of HomeGrocer.com, Kelly Ford complained when the site was redesigned and its accessible features were dropped. The Seattle company made the appropriate changes, but it was later sold to another company whose online grocery site is not accessible.

And sites that target a wide audience have been embarrassed when they have failed accessibility tests. The Bush for President campaign recently re-launched its site, only to read in the media that it didn't meet accessibility standards.

Last spring, people found that the ballots for the online primary held in Arizona were inaccessible; voting buttons were not labeled with text alternatives. As with Ford's experience with online grocery shopping, people with disabilities were denied a chance to do something they struggle with in the physical world.

"It was the one time that people who are blind could have had complete

independence when voting at the polls, and they blew it,” said Cynthia Waddell, who helped the city of San Jose become the first major municipality to address the accessibility of its Web sites.

## **CHANGE COMES SLOWLY**

Not everyone agrees that Web sites should be required to include the kind of clues that Home Page Reader and other screen recognition software can use. At a hearing in February, a House subcommittee heard testimony whether the Internet was a “public accommodation” as defined by the ADA, and much of the testimony was against the idea.

“It would be hard to find a better way to curb the currently explosive upsurge to this new publishing and commercial medium than to menace private actors with liability if they publish pages that fail to live up to some expert body’s idea of accessibility in site design,” Walter Olsen, a senior fellow at the conservative Manhattan Institute, told the House Judiciary Subcommittee on the Constitution.

And many who call for better accessibility favor encouraging more enlightened design, rather than forcing it. Gregg Vanderheiden, director of the Trace Research and Development Center at the University of Wisconsin at Madison, and others, speak of a future which “universal design” allows all people to access Internet content, no matter what their capabilities are or what type of device they are using. Rather than build sites that use only text or that have separate sites for people with disabilities, they advocate designing sites that transform gracefully, recognizing the special needs of the user as soon as they load onto the screen. And despite the effort IBM has made promoting Home Page Reader, the special-needs group remains a bit player in the corporations cast - only 17 employees out of a work force of more than 300,000. Only in the past three years has the company bothered to file for patents on technologies for people with disabilities, and despite a company-wide directive last year that all IBM products and Web sites must be accessible, Chairman Louis Gerstner has not talked publicly about the need for the industry to follow suit.

Like IBM, Microsoft has widely advertised its accessibility effort, but it employs just 50 people and has been active since 1998. Before then, the company did not work with developers of accessibility software, so blind users had to wait nine months before being able to work with accessible versions of new systems such as Windows 95.

“It’s very easy for our products to get lost because we have very small vol-

ume and there are many other very important products in which we get lost,” IBM’s Thatcher says. “It’s hard for IBM to sell so few products.”

For Guido Corona, Home Page Reader has been a godsend, and he is back to being an Internet evangelist. Many sites still confound him, but most weeks, he spends hours searching the Web for news, the latest price of IBM stock, downloadable books and music, and stories about science. On his desk at home there are books by Tom Clancy and Thomas Mann he has scanned into his computer to be read back to him later.

In the 19th century, when the masses were learning to read, the divide between the blind and the sighted populations widened. Those who could read suddenly had access to information about the world, while the blind had to rely on hearsay. Later, they could listen to radio and television, and Braille texts and recorded books helped. But none of it was available widely enough or quickly enough to provide access to information.

“Now with the explosion of information on the Internet, that gap becomes even greater because the amount of information out there is growing exponentially, but the blind population will start with the same methods,” Corona says. “So when the Internet becomes all of a sudden accessible, it’s truly opening the floodgate of knowledge, of information, of self-worth, of education, of being part of this global village. And that is awesome.”

*Editor’s note: If Guido Corona’s name sounds familiar to some of you there’s a good reason. He was the keynote speaker at the July 2000 Summer Technology Institute held in Austin.*

Programming

## **Tips for New VI Teachers**

By Nancy Toelle, Coordinator

Quality Programs for Students with Visual Impairments  
and Ann Rash, Teacher Trainer, TSBVI, VI Outreach

This article is the first in a series based on a session presented at the “Helen Called Her Teacher” conference sponsored by Texas School for the Blind and Visually Impaired (TSBVI). It is intended to help new teachers look at the components of service delivery to meet the unique needs of students with visual

impairments. The concerns stated below are a representative sample of those expressed by new and not-so-new teachers.

This article addresses the issue of how a new teacher determines how his or her school day is to be spent. The fact that this is a pressing issue can be appreciated when hearing the comments of new teachers, who say they are working night and day to meet the needs of students, staff, and parents.

## HOW MUCH AND WHAT KIND OF VI SERVICE

### CONCERN:

How much and what kind of VI service is indicated in your student's IEP?

### SUGGESTIONS:

This is a good time to start compiling a "teacher file" on your students that will help you keep track of a lot of important information. You may find it helpful to start a notebook or fact sheet on each student. This will become your "travel" notebook or file. Your preference for a notebook or a portable file holder will determine your final product.

Find yourself a comfortable spot, take a few of your student's eligibility folders, and go through their most recent IEP paperwork, looking for the pages indicating the amount of service to be provided by everyone to the child. Also gather together *all* IEP forms, so you will have a good idea of what the child's total program will be. *Please note: a best practice that we are encountering more and more is to find integrated IEPs that have been developed by a student's multidisciplinary team.* When looking at IEP goals and objectives, look for those with a visual, tactual, or auditory component. Any of these could be the responsibility of the VI teacher (to provide direct instruction, materials, consultation, etc.). Look on the signature page for the name of the VI teacher involved in developing the IEP; he/she may be able to offer insights into how the IEP was developed. As you gather information on each student, devise a form on which you could keep needed information on all your students, such as date of birth, home address and phone number, campus and teacher name. Remember this is for your use and does not have to be elaborate or computer generated; a plain piece of paper divided into sections works just fine. This will be handy for contacting parents and teachers when you don't have the student's folder with you.

## **MAKING A CHANGE**

### **CONCERN:**

If you were not a member of the IEP Committee that made the recommendation for this amount of time, and you feel a change is needed, do you know your options to make a change?

### **SUGGESTION:**

The first and best option is to get to know the student and the program he/she is attending. One of the most practical approaches is to use a student-appropriate objective standard as you observe and work with the student. For example, use a pre-reading checklist for a young, academically able child or an observation checklist of critical features of effective programming for students with multiple impairments. (These instruments, and others, can be found in the TSBVI Assessment KIT and in the RSPI, Regional Student Performance Indicators.)

Be aware, this takes time. If you are scheduled to see a student only a small amount of time, such as a half-hour per month, you will not have enough time to really get to know the student. Since you can't be of much help to anyone if you don't know the student, it's important that you find a way to spend more time with him/her. Remember, taking this time is not prohibited by the IEP Committee. If, after getting to know the student, you feel more instructional or consultation time is needed, an IEP committee meeting will be necessary to make that change.

On the other hand, after spending some time with the student in his/her program you may feel too much time has been allowed for you to work with him/her. Before proposing changes to the IEP team, you should find some way to objectively measure student need that substantiates your thinking. It will then be a decision of the IEP committee to make a change in the amount of services.

Programming

## **SCHEDULING TIME**

### **CONCERN:**

How do I address scheduling time to better meet my student's needs in an IEP meeting?

### **SUGGESTION:**

You may be flexible in the way you schedule time with the student. For

example, a “best practice” goal for a student with visual and multiple impairments would be to observe the student in every environment and activity that he/she is engaged in throughout the school day. This would necessitate several visits at different times of the day to observe the student’s program and determine VI specific needs. (Is the occupational therapist using a spoon the child can see, and presenting it at an appropriate distance and in his/her field of vision?) If the team is writing activity routines, you need to join the team with VI specific suggestions. If the team has never written an activity routine, it is your responsibility to initiate this important programming. If IEP specified time for this child is described in the IEP document as “twelve hours during the first twelve weeks of school and four hours per month thereafter” you could be flexible about your scheduling. You could spend longer chunks of time getting to know the student. If necessary, you could make multiple visits during the course of the week to his/her service providers to work as a team. Once things are running smoothly, the student and staff may need you can settle into a more regular schedule each week. The amount of time meets the IEP requirement, and the flexible scheduling allow you better to meet the needs of the child and the team. This approach may also be needed with your low vision or blind students who are academically able.

If this approach seems overwhelming, we suggest you try it with just one student. It won’t be long before you, your student, and the team start to experience the benefits.

**PRINT AND/OR PERSONNEL RESOURCES**

**CONCERN:**

Do you have print and/or personnel resources readily available to you?

**SUGGESTION:**

The first step is to become familiar with what your district has to offer. Go looking for the VI materials stashed away in schools, or the nooks and crannies around the district. Next call your education service center VI Consultant and ask for help. In the meantime, some of our favorites are: *The Perkins Activity Guide*, *Beginning with Braille* by Anna Swenson, *APH Bright Sights Kit* and *Work Play Trays*, the *Every Move Counts* multi-sensory assessment, the Internet (including TSBVI’s website <[www.tsbvi.edu](http://www.tsbvi.edu)>) and materials available through the TSBVI curriculum department such as the *Learning Media Assessment* and the red *Low Vision* book (listed on the TSBVI website). You can

probably access the Internet in your school library.

## TIME TO PLAN LESSONS

### CONCERN:

Do you make the time in your schedule to plan lessons with VI materials and resources?

### SUGGESTION:

First, we acknowledge the fact that as itinerants we have little time, if any, set aside to plan. What time we have to spend in the office (if we have one) is often spent writing reports, record keeping, making or returning phone calls, or fighting fires. Without time to plan properly, lessons are never really meaningful, sequential, and building toward acquisition of the key skills needed. The teacher's anxiety level goes up and satisfaction with the job goes down. We suggest that as you develop your schedule, write in time to plan your instruction and to prepare for it as well. AND don't forget to eat lunch.

We hope that we've addressed at least some of the concerns that you, as new teacher, may have. We would love to hear from VI teachers who have their own suggestions. For a thought provoking article on a related topic, read "Observation: The Other Four-Fifths of the Day," from the Winter 1999 issue of *SEE/HEAR*. Find it in the *SEE/HEAR* Newsletter Index on the TSBVI website. Until the next time, we hope you can feel good about helping all your students, that you manage to make it to all your schools, and that there are no flats or other road mishaps in your future.

In our next article we will try to give suggestions that address the concern: Do you feel comfortable deciding what to do with your students? If you have specific concerns related to this topic that you would like us to address, please feel free to contact Ann Rash by phone at (512) 206-9224, or e-mail her at [AnnRash@tsbvi.edu](mailto:AnnRash@tsbvi.edu).

# **Educational Services in Texas for Children with Visual Impairments and Deafblindness**

By Cyral Miller, Director of Outreach and  
Kate Moss, Family Specialist, Texas Deafblind Outreach

Texas parents are often confused about the range and type of educational services available to their school-aged children with visual impairments or deafblindness. It can be hard to advocate effectively without a full understanding of service delivery options.

On his/her 3rd birthday, services for a child with visual impairments or deafblindness move from an ECI program to the local school district. At this time the Individualized Family Services Plan (IFSP) that addressed the needs of the child and the family is no longer used. Instead an Individualized Educational Plan (IEP) is developed by a team made up of the parent, professionals and (when appropriate) the child. The focus is no longer on the family and child as strongly, but rather focuses more on the child's educational programming. This team is mandated by federal and state law to assess the child's performance and determine appropriate services for provision of a free, appropriate public education that addresses the specific needs related to his/her visual impairment/deafblindness. Services may be provided in a regular classroom setting, a self-contained setting, resource classroom, residential setting (such as Texas School for the Blind and Visually Impaired or Texas School for the Deaf), or in a combination of settings. Children with chronic health conditions may need to be served at home. A physician must recommend the need for these services.

**Programming**

## **LOCAL INDEPENDENT SCHOOL DISTRICTS (ISD)**

Please check with your local ISD for web addresses, or you can search the Texas Education Agency website <[www.tea.tx.state.us](http://www.tea.tx.state.us)>.

Services for students with visual impairment are most often provided by a local district or a special education coop which hires teachers with specialized credentials. Typically this means that an itinerant (traveling) vision teacher will travel from school to school to work with the student and/or his/her educational team. The types of services provided by the Teacher of the Visually Impaired include:

- Completing a Functional Vision Evaluation (FVE) and a Learning Media Assessment (LMA)

- Assisting the team in appropriate adaptation of all assessment materials and techniques to address the child's vision impairment
- Attending all IEP meetings
- Planning with the team to develop appropriate IEP goals and modifications that address the sensory impairment (the expanded core curriculum)
- Providing direct and consultative services to the child and team members to support general instruction (assist in developing routines, providing Braille or large print materials, etc.)
- Providing direct instruction to the child in specific areas such as braille, daily living skills, vocational planning, instruction in visual efficiency, vision-specific technology adaptations, etc.

Services will also often be recommended from an Orientation and Mobility Specialist who can provide instruction in safe and effective movement and travel skills.

Services for the child with deafblindness should also come from a Teacher of the Deaf and Hearing Impaired. This teacher may work directly for the local district or he/she may work for the Regional Day School Program for the Deaf (RDSPD). Local ISDs may contract with the RDSPD to provide services. The Teacher of the Deaf and Hearing Impaired has these responsibilities:

- Assisting the team with the adaptation of assessments to make sure they address the hearing impairment
- Attending all IEP meetings and make recommendations to the team in developing IEP goals and objectives that address auditory issues such as auditory training, communication skills, speechreading skills, etc.
- Providing direct or consultative services to the child and/or his educational team to support general instruction
- Providing direct instruction to the child in appropriate areas such as the development of sign language, auditory training, speechreading, language development, etc.
- Providing direct or consultative services to the child and/or his educational team on the use of assistive devices such as his/her hearing aid, cochlear implant, FM system, TTY, etc.

## **REGIONAL DAY SCHOOL PROGRAMS FOR THE DEAF (RDSPD)**

Learn more about RDSPD programs through the TEA website by going to <<http://www.tea.state.tx.us/deaf/>>.

Eligible children with deafblindness may receive all or part of their services from an RDSPD program. There are a number of programs in most regions of the state, although not necessarily a program located in every district. If a school district hires their own Teacher of the Deaf or Hearing Impaired the services related to a deafblind child's hearing loss may or may not come from an RDSPD program. Also, some children who are deafblind may have a mild hearing loss and do not qualify as auditorially impaired for the purpose of receiving services from RDSPD. All of this is determined at the IEP meeting. RDSPDs often have a center-based program or special classrooms located on the campus of a neighborhood school. Students served by an RDSPD program may receive consultative or direct services (auditory training, language development, etc.) from an RDSPD Teacher of the Deaf and Hearing Impaired, assessment support, and/or technology such as FM Trainers.

## **EDUCATION SERVICE CENTERS (ESC)**

ESC websites are accessible from the TEA website. Go to <<http://www.tea.state.tx.us/special.ed/escinfo/director.html>>.

The local ISD and RDSPD programs receive support from the Education Service Centers (ESC). There are twenty ESCs, each serving a specific region of the state. The ESC may provide direct services to a child with a visual impairment, but generally it supports Teachers of the Visually Impaired and Orientation and Mobility Specialists who are employed by the districts. This support is provided primarily through planning, supplemental funding, and in-service development in its region. Each ESC must develop, with stakeholders, a regional plan to jointly determine how to improve student performance. These plans address many areas of educational services and are required in order to receive supplemental funding from the Texas Education Agency. Since 1998, each ESC also has a designated staff member who is a Deafblind Specialist, with specific duties relative to this population of students with combined hearing and vision losses.

## **TEXAS SCHOOL FOR THE BLIND AND VISUALLY IMPAIRED (TSBVI)**

For detailed information about TSBVI go to our website. It is located at <[www.tsbvi.edu](http://www.tsbvi.edu)>.

TSBVI is a special public school established by the Texas Legislature to provide specialized and intensive services which focus on the unique learning needs of students with visual impairment, including those with additional disabilities.

### **REGULAR SCHOOL-YEAR PLACEMENT**

TSBVI offers a comprehensive educational program during the regular school year. Students must be referred by the local IEP committee and admission is considered on an individual basis. Curricular offerings include regular academics, functional academics, and basic skills programming for 6-21 year-olds. Services are provided during the school day and in residential programming.

### **SUMMER SCHOOL**

There are a variety of summer school programs that range in duration from 1-6 weeks. Parents can make application directly to TSBVI for summer school programs. Last year's summer offerings included: elementary and secondary level enrichment programs, career education offering non-paid work training and paid work experiences for secondary students; specialized programs in technology and mathematics, and specialized camps for students with visual and multiple disabilities including deafblindness.

### **SHORT PROGRAMS**

Beginning in 2000, short courses are being offered at TSBVI during the regular school year to students enrolled in their local ISD programs. A course in daily living skills is offered over a series of four weekends in a single school year. Two week long technology programs have been scheduled for this year. A week of individualized study is being provided in six sessions throughout the year. Many new programs will be developed from year to year. (See the Summer 2000 issue of *SEE/HEAR* for more about these programs, or visit the TSBVI website at <[www.tsbvi.edu](http://www.tsbvi.edu)>.)

### **OUTREACH**

There are three branches of Outreach focus: Statewide Programs, Visually Impaired Outreach, and Deafblind Outreach.

Statewide programs are in place to manage the American Printing House for the Blind Quota Funds used to purchase and disseminate (free to districts)

specialized materials such as brailers, braille paper, light boxes and so on. The annual statewide registry of eligible students is conducted at TSBVI. Other statewide functions are coordination of teacher preparation issues, mentoring for VI teachers and O&M specialists-in-training, and statewide staff development. TSBVI works collaboratively with all twenty Education Service Centers, as well as with universities, the Texas Commission for the Blind, and other related agencies.

Visually Impaired Outreach staff provide training and support to professionals working with babies and toddlers 0-5, professionals serving students 6-21, and to their families. The team works with individual students or supporting a district wide program for visually impaired students. The Technology Loan Program is part of this branch of Outreach.

Texas Deafblind Outreach is a similar team. In addition to support for professionals and families, there is a focus on transition issues related to the post-educational world. Texas Deafblind Outreach also coordinates the INSITE curriculum training for professionals working with children 0-5 with multiple sensory impairments.

Much of the focus of Outreach is on helping families and professionals. Activities include directly consulting with a family and school program and suggesting programming recommendations, giving workshops, conferences, or small local in-service opportunities, and by providing leadership in statewide issues and training in the area of visual impairments and deafblindness.

Programming

## **CURRICULUM**

This department develops and publishes a variety of materials for teachers and parents on topics including orientation and mobility, a curriculum for visually and multiply impaired students, and a paraprofessional handbook.

## **TEXAS SCHOOL FOR THE DEAF (TSD)**

Learn more about the various programs available for students at TSD by visiting their website. Go to <http://www.tsd.state.tx.us/>.

Texas School for the Deaf (TSD) provides residential school placement, summer school programming, a special transition program, workshops for parents of students attending TSD and serves as an Educational Resource Center on Deafness. Unlike TSBVI or other residential programs, parents may inde-

pendently refer their child to TSD or the referral may come as a result of the IEP committee's recommendations. Children who attend TSD may have previously attended Regional Day School Programs for the Deaf (RDSPD) or inclusive programs in their home school districts.

## **TEXAS COMMISSION FOR THE BLIND (TCB)**

Although Texas Commission for the Blind is not specifically an education agency, there are complementary services in the area of education available through this agency. To learn more about their role in both education and especially in rehabilitation go to their website at <http://www.tcb.state.tx.us/>.

Texas Commission for the Blind provides a variety of services. Their service focus is geared more towards non-educational needs such as in-home training in daily living skills, and tuition for summer camps. They also can assist with travel and registration costs for families attending training. The TCB children's caseworkers or transition counselors can also support the parents and student in advocating for educational services by helping them prepare for, and by attending, the IEP meeting. If the child is deafblind, the TCB also offers support to the family, the student, and the children's caseworker or counselor by providing a deaf-blind specialist. A deaf-blind specialist can determine the need for technology and services that are unique to deafblindness, such as getting and using a TTY, a vibrating alarm clock, or security devices.

## **TEXAS EDUCATION AGENCY (TEA)**

The lead agency in educational services in Texas is of course, the Texas Education Agency. To learn more about the full scope of this agency's work go to their website at [www.tea.state.us](http://www.tea.state.us).

The TEA is mandated to ensure that all Texas students are provided a free and appropriate education. The TEA helps to monitor the effective implementation of the Federal Individuals with Disabilities Education Act, as well as state and commissioner rules and regulations regarding special education services. We are fortunate in Texas to have people in the agency designated to address issues specifically related to vision or hearing impairments. Marty Murrell assists the state in advocating for and creating quality services for students who are visually impaired and/or deafblind. Sha Cowan assists the state in advocating for and creating quality services for students who are deaf and hearing impaired, and supports efforts for students with deafblindness.

There are a wide array of agencies with special roles in assisting the child with a visual impairment and/or deafblindness and their families. More information is available on each at the websites noted above. We hope you will explore further, to ensure that your child is receiving the most appropriate education possible!

## **The Importance of Touch in Parent-Infant Bonding**

by Gigi Newton, Teacher Trainer, TSBVI, Texas Deafblind Outreach

*Editor's note: In 1992, Gigi Newton, Teacher Trainer with Texas Deafblind Outreach, began to share information with our team about the benefits of massage therapy with children who are deafblind. During this time, Evelyn Guyer, a certified infant massage therapist, had begun to train individuals in the use of Bonding And Relaxation Therapy (BART) and had received a grant to train parents and others to use these techniques with deafblind children. Gigi wrote an article about some of the work being done by Evelyn and others that was published in the July 1992 edition of P.S. News (the Deafblind Outreach newsletter before SEE/HEAR).*

*Also in 1992, through Gigi and Stacy Shafer, Early Childhood Specialist with Visually Impaired Outreach, we learned about Active Learning theory from Dr. Lilli Nielsen of Denmark. Active Learning focused on providing the child with blindness opportunities to be an active participant in interactions with the environment. This approach benefits children with visual impairments by assisting in the development of body awareness and motor skills, cognitive skills such as comparing and contrasting qualities (heavy, light, soft, hard, smooth, rough, noisy, quiet, vibrating, still, etc.), and choice-making.*

*In 1997, I attended a session at the National Deafblind Conference in Washington, D.C. titled "Hands: Tools, Sense Organs, Voice", presented by Barbara Miles. Her session focused on the functions of hands in cognitive, linguistic and emotional development for children with deafblindness. In May of 1999, DB-LINK published Barbara's article, "Talking the Language of Hands to Hands." This article (which is available on the DB-LINK website at <[www.tr.wou.edu/dblink](http://www.tr.wou.edu/dblink)> ) looks at the role of hands in early development for children with blindness, deafness, and deafblindness, and suggests strategies for facilitating hand development in children with deafblindness.*

*For the past several years, the Texas Deafblind Outreach team has been*

*discussing the importance of these theories and approaches in the education of children with deafblindness. Developing the tactual sense, body awareness, the use of hands, and establishing bonds of trust between the child and caregiver or instructor are key components in the child's ability to benefit from instruction. This is especially true when the child is severely visually and auditorially impaired, but is also true to some degree for any child with sensory impairments. Many early literacy and learning skills require the development of the tactual sense, the awareness and use of hands and fingers, the child's willingness to trust an instructor who guides his/her hands to explore objects and people in the environment.*

*In the summer or early fall of 2001, Texas Deafblind Outreach plans to offer a workshop for parents and members of their childrens' educational teams that emphasizes these approaches. Future editions of SEE/HEAR will also feature articles on these topics to help you decide if this workshop might be beneficial for you. Here we are reprinting Gigi's 1992 article about infant massage and the importance of touch in parent-infant bonding. Touch is a powerful way to communicate.*

Touch from another human being can be a nourishing medicine or a damaging poison. Without words, we can show affection by giving a hug or by stroking a child's arm, or we can show disapproval by using our hands to restrain a child's hand. The importance of touch for a child with deafblindness is apparent. The child will use this sense extensively to develop communication skills, to help orient in different environments, and most importantly to connect socially with others. This article focuses on the power of gentle touching and suggests ways in which touch can make a positive change in your life and the life of your child.

What does caring and loving touch do for infants? It is a necessary part of developing attachment between the child and parents. It is the beginning of communication between you and your child. Because you make him feel secure, the child learns to trust you and develops an emotional tie to you. The child's response to those feelings of security deepens your feelings of love and protectiveness towards him. It is what Dr. T. Barry Brazelton refers to as the parent and child "falling in love" with each other.

The most important thing parents can do to help develop this attachment is to first become careful observers of their child and learn how to interpret his needs. A newborn communicates his needs or feelings to his parents primarily

through crying. When a baby's cry is responded to quickly and warmly, the child begins to develop a bond or attachment to the caregiver.

When a child is not responded to he does not feel safe. As a result his sleeping, eating, and social interactions can all be affected. According to research findings, if a baby knows a caregiver will respond, the baby begins to reserve crying for more specialized needs. This finding disputes the belief that babies are spoiled by parents who respond every time to their child's crying.

Talking to a baby while responding to his cry lets him know that the caregiver understands his feelings. Over time he begins to be comforted by the voice and to understand that words are a way of communicating. This situation changes somewhat with children with deafblindness.

Babies with deafblindness will need to have more input through other senses such as touch, smell, etc. because of the information that is lost to them through their decreased vision and hearing. Try cuddling the child against your chest while you are speaking or holding his hand or foot against your cheek or chest to let him feel the vibrations of your voice. Use a consistent signal, like soft pats on the back or stroking his forehead to communicate your empathy.

The crying behaviors of infants with hearing, vision, and /or neurological problems may be different from an infant without disabilities. It may take more observation to understand what their cry means and how to respond to them. Parents might try to list times when the baby cries and note any patterns in the baby's environment that might be causing him distress. If all the child's basic needs (i.e., food, dry diapers, companionship, etc.) have been met and the child continues to cry, the parent may need to look for signs of over-stimulation. Some of these signs are: turning the body, face or eyes away; closing his eyes; arching the back; spitting up; rapid shallow breathing; changing color; hiccupping.

If the child is over-stimulated you may need to try some inventive approaches to consoling your baby. Preventively, you can try to keep your baby's daily schedule as consistent as possible. You can make the environment calming by dimming the lights, dropping the noise level, and reducing social stimulation. You may also try things like placing him in his travel chair on the washing machine so he is lulled by the vibrations. Taking rides in the car, running a vacuum cleaner, anything that produces a steady vibrating motion or monotonous sound, can also help him to relax or calm. You will have to be creative in finding the type of calming actions that work best for your child.

Moms and dads also bond with their babies by kissing, cuddling, and making eye contact. Babies with vision, hearing, or motor impairments may not receive as much feedback from this type of physical contact because of their impairment. Ask your Vision Teacher to help you decide how your baby uses his vision and how to adjust the lighting in his environment to maximize the use of his vision. For example, the baby might see your face better if the light came from behind him so he does not have to look into a glaring light when he turns to you. To keep from startling a baby who may not hear your voice, a “signature” scent (hand lotion or perfume) may provide a cue that you are near.

Infants with seizure disorders or motor impairments may not respond well to touching and holding. Certain types of touch may actually trigger a seizure in some children with seizure disorders because it is stressful. Some children are tactilely defensive or they have abnormal muscle tone. When a baby does not show a typical response to a parent’s attention the parent may interpret the baby’s response as rejection. The parents may begin to hold the child less often. However, the child’s atypical response to touch may relate to muscle tone rather than to feelings about his parents. With these children, it is critical for the parents to learn to touch their child in a way that is acceptable and pleasurable to the child.

**Programming**

Physical therapists and occupational therapists can help parents discover what types of physical touch their child can tolerate and learn to enjoy. They can also make suggestions about textures (for clothing, bedding, etc.) that may be more pleasing to the child. Parents may want to start with a few minutes of touching, and increase the time gradually as the child can tolerate it. Often children prefer firm pressure on their arms and legs as opposed to light stroking. When using light strokes move in the direction of the hair growth, not against it. Avoid applying pressure on the spine. As the child becomes comfortable with being touched he will become more comfortable touching things and people in his environment. If a child does not enjoy touching, he will have a difficult time learning to explore his surroundings.

In *Touching* by Montagu we learn that holding and rocking a baby has physiological and emotional benefits. Touching increases the baby’s cardiac output, promotes respiration that in turn discourages lung congestion and helps the baby’s gastrointestinal function. The movement of rocking often helps in digestion and absorption of food.

During normal home activities such as diapering, bathing and bedtime, incorporate a few minutes of gentle touching. Rubbing on baby lotion, cuddling before bedtime or massaging arms and legs during a bath can add an extra measure of caring to ordinary events. Sometimes these caring touches can even make a bothersome event pleasurable.

One special technique of touching that is being used to increase bonding is infant massage. Infant massage is a more structured way of touching. Many hospitals use infant massage with premature infants. Current studies seem to suggest infant massage may enhance a premature baby's physical growth and development. Infant massage is something you do with your baby as opposed to something that is done to your baby. It is a way for parents to connect with their child on a special level. Massage can help parents learn the way their baby's body looks and feels when he is tensed or relaxed; the look and feel of a gassy stomach; the difference between pain and tension.

## RESOURCES AND REFERENCES

If you want information about infant massage training contact: The International Association of Infant Massage Instructors, E. Micki Riddle, R.N., Ph.D., Executive Director, 1891 Goodyear Avenue, Suite 622, Ventura, CA 93008 or phone (805) 644-8524. There is also a website; go to <<http://www.iaim-us.com/>>. The following books can be ordered through the website, by calling toll-free (888) 448-9489 or by e-mailing IAIM4US@aol.com:

*Baby Massage: Parent-Child Bonding Through Touch*, Amelia D. Auckett, Harper Collins, 1989.

*From the Hand to the Heart* (book and video tape), Evelyn Guyer. This is a book for parents and caregivers who care for disabled individuals.

*Infant Massage: A Handbook for Loving Parents*, Vimala Schneider McClure, Bantam Books, 2000.

*Touching*, Montagu, A., Harper Collins, 1986.

Another booklet that may be useful to parents is available from the Blind Children's Center, P.O. Box 29159, Los Angeles, CA 90029 or from their website at <<http://www.blindcntr.org/>>:

*Move With Me: A Parents' Guide to Movement Development for Visually Impaired Babies*, Blind Children's Center (also available in Spanish).

## Tell Me, and I'll Forget

Terry Murphy, Executive Director, Texas Commission for the Blind

The title of this article is from the old Native American proverb: *Tell me, and I'll forget. Show me, and I may not remember. Involve me, and I'll understand.* The first part of the proverb reminds me of a class in which the drone of the teacher reading from a textbook never quite penetrated my preoccupation with the more important subject of lunch the next period. The results from those occasional days, of course, you already know. Inevitably there appeared on my desk - the TEST. If I could only remember what I'd heard! Nothing. The only thing I knew for sure was that the answers to questions 3 and 7 were definitely not "hamburger" and "french fries."

Fortunately for me, not many of my learning experiences were limited to the "tell me" variety. Most were right in step with the observation of the first occupants of our great country: I remember best those subjects in which I was fully involved. This is why I have advocated over the years for full and active consumer and parental involvement in the services the agency provides. No matter what you tell a person about blindness, until you show them the benefits of certain skills and get them involved in reaping the benefits as they learn, the information you told them won't do much good on "test day."

Test days for people who are blind are those days in which they want to independently achieve without sight something that another person does with sight, such as navigate their way to the grocery store or to work, or try out the monkey bars at school. Typical test days for parents of children who are blind are those days when they are called to participate in their child's ARD or when they are trying to locate a fulfilling afternoon activity for their child.

The Commission measures the success of its services against "test scores" of its consumers. We really celebrate when consumers graduate *summa cum laude* from our programs, which means they have gained the skills, training, knowledge, and equipment they need to be confident in their own abilities. Parents graduate with equally high honors when they have the skills to participate as a full partner in their child's educational program and have a reservoir of activities and resources for their child.

One of the major ways consumers and parents are kept involved in the learning experiences offered by the Commission is through written plans. These

plans assure that consumers and parents are not only involved in planning the outcome they expect from services, but also in planning the individual steps along the way. In our Vocational Rehabilitation Program, the plan is an *Individual Plan for Employment*. Our Blind and Visually Impaired Children's Program uses a *Family Service Plan*. Both of these formats have been revised and improved this year.

Our new family service plan is set up so that the basics we could describe as "Confidence 101" skills are covered, which when learned, will produce the highest real-life test results for families who have children with visual impairments, including children with multiple disabilities. These core services include family services, educational support, independent living skills, social-emotional development, leisure and recreational skills, prevocational skills (or future planning for children with multiple disabilities where work does not appear to be an option), communication skills, travel skills, and low vision and medical services. The plan changes as the child progresses and reaches new developmental milestones. The progress criteria then help validate that the child and parents are on the right path or suggest that another direction is better to reach the planned goal.

Coming back to the old proverb, the Commission's staff has been challenged to reinforce what they "tell" consumers and parents by getting them fully involved in the family service plan so that what is heard is not forgotten on test days. In reality, however, we can share information and the knowledge that we have gained over decades of experience, but the willingness to listen and be fully involved in core services we know are needed, rests with the people who come to us for assistance.

If you have had the opportunity to be involved with our new family service plan, we would welcome your feedback. Are we developing plans with you that involve you in a way that helps you understand why certain core skills will better prepare you and your child for the many test days coming your way? If not, what do we need to do differently? Just as important, how actively involved are you in your family service plan? Only together can we make a difference!

## **In Response**

By Dr. Phil Hatlen, Superintendent  
Texas School for the Blind and Visually Impaired  
PhilHatlen@tsbvi.edu

I often receive telephone calls and mail from both parents and educators, requesting my opinions about the educational services needed by a specific child. I recently had an e-mail exchange with an educator in another state, and I will share portions of our communication. I invite your comments and thoughts on this exchange.

### **SCHOOL DISTRICT:**

I am writing to you because I have accessed your website and am very impressed with its content. A parent in our district is going to ask that we place his son in the residential school. The parent has stated that he wishes his son to receive services for approximately two years at this specialized setting, with the intent to return him to our district for high school.

The student is performing well in our district. He receives, in our opinion, adequate support services, including orientation and mobility, OT, services from a teacher for the visually impaired, and a full-time paraprofessional. There are certain home conditions that may be playing on the father's thinking at this time.

What would you think are the most compelling reasons to maintain a visually impaired student in our district, beyond the reasons/rational applicable to sighted peers? Our staff have worked hard to make this placement work, and they do not wish to see this child removed. They feel it implies that they have failed in their educational endeavors for this student. What suggestions can you offer us?

### **MY RESPONSE:**

While I am employed by a school for the blind, I have always been an advocate for an array of placement options for blind and visually impaired students. I believe that there is no "one size fits all" approach to meeting the diverse needs of students who are visually impaired. Each child is an individual with individual needs, and these needs will change or be different, depending on degree of visual impairment, presence of additional disabilities, services available locally, and specific needs based on age and maturity. I believe that the IEP must

consider the entire array of placement possibilities yearly, because the needs of visually impaired students will change yearly.

I am a strong advocate for local placement of visually impaired students, and I urge my colleagues to always consider local neighborhood school first. On the other hand, I believe in a level playing field among all placement options. A child should not have to fail in one setting before being referred to another. I do not believe that a school for the blind should be the last option for a child. For some students, it should be the first, or perhaps, the only option.

So, what about the child who concerns you? In a perfect world he would have had a comprehensive assessment which should have included compensatory skills for academic learning, functional low vision, learning media, orientation and mobility, career education, assistive technology, independent living skills, social interactive skills, and leisure/recreation skills. All of these assessments should be done, or orchestrated, by the qualified, credentialed teacher of the visually impaired. Based on the outcome of these assessments, an IEP should be developed that reflects the strengths and needs of the student in all of these areas. Then goals and objectives are written to meet the needs identified through assessment. I would expect that most blind and visually impaired students would have at least one goal in each area assessed.

It is only after assessment and IEP development have been completed that placement is considered. Giving careful consideration to frequency and duration of instruction for every goal and objective from the teacher of the visually impaired, a school district must determine whether it has the resources to meet the needs. In some cases, teachers from related services might be the primary service providers, and in the case of orientation and mobility, a specialist will provide the instruction. Of course, the classroom aide should never, ever, take the role of instructor. She may only reinforce skills and knowledge learned from the teacher. The crucial question is how many hours per week are needed for direct instruction from the teacher of the visually impaired. Today, many educators are saying that every blind and visually impaired student should have at least one hour per day of instruction from the teacher of the visually impaired. Any less than this, places the student at risk for not learning skills unique and necessary for blind and visually impaired persons. Some students are going to need more than an hour a day. What about them? Does your itinerant teacher have a schedule that is so flexible that she can provide for those students who have intensive needs?

What are the resources available to the student from the school district? Are they adequate to meet the child's needs? If not, will the district increase its resources to meet those needs? If this is not possible, will the district refer the child to a program (such as the residential school) that can meet the intensive needs of a child? Is the district reluctant to make an out-of-district referral because it feels like failure? What if the district is doing all it can, and still cannot meet the unique, intensive needs of a child?

Can we, you and I, discuss this child's needs on a level playing field? Are we both able to say that inclusion is simply one more option for placement and should be the goal, but may not be appropriate for all students? Can we agree that, for those children appropriately placed in a school for the blind, that is their Least Restrictive Environment (LRE)? Can we both say that philosophy does not drive our decisions, but consideration for the individual needs of a child is how we make decisions about placement.

I wish you and the family well in your decisions. Please let me know if I can provide you with further information or clarification.

## **Legislative Update**

Compiled by Edgenie J. Bellah, Program Consultant  
Texas Commission for the Blind  
and Cyral Miller, Director of Outreach  
Texas School for the Blind and Visually Impaired

This year parents and professionals will want to stay current on both Federal and State legislative actions, as the Texas Legislature will come back into session January 2001.

The American Foundation for the Blind's "Words from Washington" recently reported on two federal issues of interest. The first is pending Federal legislation that would allow qualified O&M specialists, rehabilitation teachers and low vision therapists to become eligible providers under Medicare. This would result in the professionals being reimbursed from Medicare funds, which can be used to meet the budget needs. HR2870, the Medicare Vision Rehabilitation Coverage Act of 1999, has over 100 co-sponsors in the House. To see the text of the current draft, you can go to <[http://www.medicarenow.org/advocacy\\_legislation\\_bill.htm](http://www.medicarenow.org/advocacy_legislation_bill.htm)>. This bill

would, for the first time, include vision rehabilitation services under the Medicare program. Once passed by the House, this bill will move to the Senate for its action.

The second is that the Federal Communications Commission (FCC) has adopted rules for large broadcast stations and program distributors, to increase the availability of video description for television. With video description, narration inserted into television programming describes actions or visual clues to supplement dialogue and soundtracks. Using a separate channel, viewers can access critical information that enhances their television programming. The new rules, to go fully into effect by April 2002, will require a minimum of fifty hours per quarter (about four hours a week) of prime time and/or children's programming for large broadcasters in twenty-five major television markets. Rules will also increase accessibility of emergency information.

Another Federal issue we have been following that has tremendous impact on the lives of Texans is Medicaid. There are efforts underway nationally to extend health care coverage to more children through Medicaid and the Children's Health Insurance Program. All states were expected to have CHIP completely implemented this fall, or they would have to pay back whatever was not spent. Because the CHIP program was approved by the U.S. Congress when the Legislature's session had already ended and Texas just started enrollment in the spring, it has been reported that our state may have to pay back a significant portion of CHIP funding for missing the deadline. Unless efforts in Congress to extend the deadline for implementation of CHIP to bigger states such as Texas and California are successful, the loss of revenue could cut down on future efforts to secure health care coverage for children now falling through the cracks.

There is also a pending federal lawsuit on Texas' implementation of Medicaid for children, and it appears likely that there will be legislation proposed in the next State legislative session to address concerns with this program. If you are interested in learning the specifics of the Medicaid lawsuit, you can go to <http://www.main.org/txchip/index.html>. Another hot topic families will be called to voice their opinions on is a movement to simplify Medicaid. The Texas CHIP Coalition is committed to making the TexCare Partnership a success for our uninsured children. However, unless the eligibility process for children's Medicaid is simplified to mirror that of CHIP, the TexCare Partnership will not reach its fullest potential. The Texas CHIP Coalition's proposal is simple - make the application processes for children's Medicaid and CHIP the same, so when a

family mails in a TexCare Partnership application, it is complete. Other proposals include allowing mail-in applications and recertifications, making the verification and documentation policies identical to CHIP, eliminating the asset test, and adopting twelve months continuous eligibility.

Of particular interest to our readers are the following three state issues:

- Once the Texas Legislature gathers in January, we may see further debate on the benefits of specialized services for people who are blind. Given past legislative experiences, legislation may be proposed to further consolidate health and human services.
- The Texas special education system recently updated State Commissioner rules affecting special education, in part to more closely align them with the Federal Individuals with Disabilities Education Act, amended in 1997. Proposed changes were opened for public comment in early fall, and by the time you read the final amendments to 19 TAC Chapter 89, Adaptations for Special Populations, Subchapter AA. Special Education Services may be posted on the TEA website at [www.tea.state.tx.us/rules](http://www.tea.state.tx.us/rules). There were changes proposed in the eligibility criteria for visual impairment and deafblindness as well as significant revision of sections detailing procedures for provision of services to students placed by their parents in private schools.
- The new Commissioner rules mention certified teachers of the visually impaired as necessary team members for many parts of the special education services provided to visually impaired and deafblind students. The State Board for Educator Certification has been reworking the entire teacher certification process in Texas for both regular and special education. Information provided by the Alliance of and for Visually Impaired Texans (AVIT) indicates that the SBEC is planning to continue requiring specialized credentials for these teachers. That is good news for those who were apprehensive that this kind of expertise might no longer be required. However, there is a concern that decisions about how the VI credentials will be defined will be made too late, after re-vamping all the other systems for regular and generic special education teacher certification. Without quick action, there will be a time while systems for teacher certification in visual impairment are being designed and implemented during which no new teachers will be approved, aggravating an already existing shortage in VI teachers.

Any legislative session brings the promise of surprises. Families and professionals who want to stay informed can research legislation at <http://www.capitol.state.tx.us> and be prepared to contact their Representatives and Senators to advocate for services they feel are important.

## **National Braille Press**

### **Meeting the Growing Demand for Braille**

Reprinted with permission from National Braille Press Website

To achieve full participation in the work place, family activities, and civic affairs, blind people need access to the printed word. For persons with total or profound loss of sight, braille is the only medium for true literacy. They cannot see large print, and although tape recorders and synthesized speech have tremendous benefits, they are no substitute for real reading. The tape recorder did not cause sighted people to abandon print, nor did the radio displace newspapers.

Braille also gives blind people more options in life. Recent studies have demonstrated the close correlation between early braille literacy and higher employment rates and income, and more time spent on reading in adulthood. For example, in a survey of adults age 18-55 who were blind since infancy, those who reported extensive use of braille had a far lower unemployment rate (33%) than did the group as a whole (58%).

As the benefits of braille literacy have become better understood, blind people, parents, and others have led a national movement to ensure that blind children have the opportunity to learn braille in public schools. Currently, twenty-nine states have passed braille literacy bills. This new legislation, advances in technology, and the spirit of accommodation inspired by the Americans with Disabilities Act have escalated the demand for braille.

### **THE ROLE OF NATIONAL BRAILLE PRESS**

Materials in braille used to fall into three categories: religious publications, leisure reading, and schoolbooks. National Braille Press was founded in 1927 to provide blind people with practical information to be responsible and productive citizens. Our books, often developed with blind people as authors or co-authors, are distinct for their subject matter, quality of braille, readability, and affordability.

Although books in braille are more expensive to produce than print, we adhere to a policy of charging prices no higher than those for comparable editions for sighted readers. Charitable gifts and grants make up the difference.

We also transcribe magazines, menus, guides, government documents, and other print items in a self-sustaining contract services program. Nearly half of our employees are blind and fill positions at all levels in our organization.

## **PROGRAMS**

Children's Braille Literacy, our literacy program, instills readiness and motivation to read. We re-manufacture classics and contemporary picture-story books, donated by publishers, in alternating print and braille pages. These unique books enable parents and children, whether sighted or blind, to read together in the home. Through the catalog, which is available at <[www.nbp.org](http://www.nbp.org)>, families can find interesting publications such as: *Humpty Dumpty and Other Touching Rhymes*, *Just Enough To Know Better*, and *How to Do Homework Without Throwing Up*.

We are also celebrating our tenth year having a children's braille book club! Each month, we offer a new print-braille title for ages preschool through third grade, and for the same price as the print book! Membership in the club is free, entitling you to receive monthly print or braille notices, which describe the book of that month. You can order it if you want, or not. There is no obligation to buy. Or, you can join the club and automatically receive a print-braille book each month for \$100.00. Charge your membership today and start building a library for the whole family.

## **COMPUTER ACCESS**

A variety of technical manuals, reference cards, and guides help blind people get started and keep abreast with software and Internet applications. These publications are particularly important for job readiness and performance.

## **SELF-HELP**

Among our most popular materials are books for self-improvement and life-long learning. They include books and periodicals on employment and the job search, health and wellness, child care, consumer guides, handicrafts, current affairs and writing.

For more information about the National Braille Press, please call (800) 548-7323 or access the website at <www.nbp.org>.

## **New List for Blind Parents Now Available**

The Committee on Parental Concerns and the National Federation of the Blind announced recently that they are sponsoring a blind parent mailing list that creates a forum for blind parents to share their experiences. Topics may include but are not limited to solving logistical problems (such as how to manage a couple of wiggly toddlers at a shopping mall when you need one hand for your cane and the other to carry packages) and emotional issues (such as dealing with the public, handling a child's embarrassment about blindness, etc.). Parents are also encouraged to share resources such as arranging the exchange of print/braille books. There will also be occasional posts concerning topics of interest to blind persons and/or members of the National Federation of the Blind.

To subscribe to the list, send a message to <listserv@nfbnet.org>. In the body of the message put: subscribe blparent (speech synthesizer users note that listserv has 8 letters, no "e" on the end, and "blparent" is b-l-p-a-r-e-n-t).

You can also reach the NFB NET BBS via the World Wide Web at <http://www.nfbnet.org>, via FTP at <ftp://ftp.nfbnet.org>, or by pointing your Telnet client to <nfbnet.org> or <209.98.54.33>. You can also call using a conventional modem by dialing (612) 869-4599.

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# CLASSIFIED

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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>.

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## **2001 Texas Symposium on Deafblindness “Communities and Connections”**

at the Radisson Hotel Central Dallas  
February 16-17, 2001

Texas Deafblind Outreach invites parents, adult family members, and professionals serving or planning to serve individuals with deafblindness (ages 0-22) to attend this event which features state, national and international speakers such as Dr. Jan van Dijk, Dr. Linda Mamer, Dr. Sandra Davenport, Sally and Andrew Prouty, Tom Miller, Barbara Miles, Steve Perreault, Marsha Dunn Klein, Marlyn Minkin, Dr. Lauren Lieberman, Millie Smith, Cathy Allen, Edwin Carter, Rosie Yanez, and others. This conference features general and breakout sessions on topics such as interveners, van Dijk methodology, sexuality, mental health issues, family life, eating issues, recreation and fitness, self-determination, use of routines and calendars, adult services, CHARGE, Usher, and Congenital Rubella Syndromes.

Co-hosting our Friday evening social will be the Deaf-Blind Multihandicapped Association of Texas. There will be a variety of opportunities for networking and socializing including an awards banquet on Saturday honoring individuals who have made a difference in the lives of Texas children with deafblindness.

Registration, travel and child care funding assistance is available to parents and other adult family members from Texas who wish to attend. Limited spaces are available to out-of-state participants.

### Registration Rates:

Parents, Family Members, Professionals - \$150

Paraprofessionals - Free

Out-of-State Participants - \$250

**Registration Deadline: January 10, 2001**

## **INSITE: A Home-Based Model for Infants, Toddlers & 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, call Gigi Newton at (512) 206-9272, or e-mail her at GigiNewton@tsbvi.edu.

**Houston, Texas**  
Part II - Jan. 30-31  
& Feb. 1, 2001  
Contact: Jake Pino  
(713) 744-6378

**Mt. Pleasant, Texas**  
Part I - June 4-6, 2001  
Part II - June 27-29,  
2001  
Contact: Donna Clopton  
(903) 572-8551

**Austin, Texas**  
in May 2001

## **Moving the Edge 2000 Annual TASH Conference**

December 6-9, 2000  
The Fontainebleau Hilton Resort and Towers  
Miami Beach, Florida 33140

This year's TASH offers over 300 cutting-edge sessions on issues that affect the lives of people labeled with disabilities, with particular focus on those who have been labeled with "severe or multiple" disabilities. Presenters include people with disabilities, parents, educators, researchers, direct support professionals, and many committed and knowledgeable others who work everyday to ensure the full participation of all! They will be offering practical strategies and information that you can put to use immediately. Representatives of many of the leading disability-related manufacturers, publishers, and suppliers will also be exhibiting.

For more information  
Call: (800) 482-TASH (8274) or (410) 828-8274  
Website: <[www.tash.org](http://www.tash.org)>

## Spring Short Classes at TSBVI

### I. Technology Week (secondary students)

JAWS for Internet - February 25-March 2

### II. Math Week (secondary students)

Adaptive Tools & Technology for  
Accessible Mathematics - April 1-6

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

\* High School Students January 21-26

\* Middle School Students February 4-9

\* Elementary School Students March 18-23

For additional information, contact:

Dr. Lauren Newton, Principal of Special Programs

phone: (512) 206-9119

e-mail: LaurenNewton@tsbvi.edu

## Regional Workshops

December 1, 2000

### **Assessing Technology Needs of Students with Visual Impairments**

Location: Region IV ESC, Houston, TX

Presenters: Debra Leff, Region XIII ESC

and Cecilia Robinson, Region IV ESC

Contact: Cecilia Robinson, (713) 744-6379

December 5-6, 2000

### **Putting the Pieces Together:**

### **Effective Teaching Strategies for Children with Severe Disabilities**

Location: Region I ESC, Edinburg TX

Presenters: Sharon Davis, Michelle Goebel & Theresa Spong, Region III ESC

Contact: Peter Graves, (956) 984-6165

December 11, 2000

**Braille-N-Speak: Beyond the Basics**

Location: Region XIII ESC, Austin, TX

Presenter: Debra Leff, Region XIII ESC

Contact: Debra Leff, (512) 919-5354

December 14-16, 2000

The Arc of Texas and Region XX ESC Present

**The 8th Annual Inclusion Works! Conference: Diversity Shines**

Location: San Antonio, TX

Contact: (800) 252-9729

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, TSBVI

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, TSBVI

Contact: Kitra Hill Gray, (972) 348-1580

January 29, 2001

**Intermediate Level:  
Using Routines with Students with Multiple Impairments**

Location: Region XIII ESC, Austin, TX

Presenter: Millie Smith

Contact: Debra Leff, (512) 919-5354

January 31, 2001

**Beginning Level:  
Using Routines with Students with Multiple Impairments**

Location: Region XIII ESC, Austin, TX

Presenter: Millie Smith

Contact: Debra Leff, (512) 919-5354

April 9-11, 2001

**Cognitive/Communication Assessment and Interventions for Children with Multiple Disabilities**

Presenters: Dr. Charity Rowland and Dr. Phil Schweigert

Location: College Station Conference Center,  
College Station, TX

Contact: Nodya Thornton, (936) 293-3787

April 19-21, 2001

**TAER Conference**

Location: Omni Hotels, Corpus Christi, TX

Contact: Pamela Broadston, (806) 742-2345

**SEE/HEAR**  
**published quarterly:**  
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**TSBVI Outreach**  
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**Austin, TX 78756**

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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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