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**Kate’s Corner**

I count myself as blessed as I go about my work here in Outreach. We have so many resources to draw on in Texas to provide support and training to families of children with visual impairments and deafblindness and the professionals serving those families. I am privileged to work with extraordinary people at TSBVI and at agencies and organizations in the state and the nation. We have excellent partners to collaborate with such as the Deaf-Blind Multihandicapped Association of Texas, the National Association for Parents of the Visually Impaired, the regional education service centers, local school districts, Texas Education Agency, and Texas Commission for the Blind, just to name a few. Though we know there is so much more to be done for children with visual impairments in our state, we are getting there.

Kate’s Corner - continued on page 2
Bonfire of Love
By Ronnie Wells, Parent, Nevada, Texas

This seemed to me to be the greatest news of all. I could not wait to get to the nearest phone and call my husband to tell him, “No more bandanas!”

My son Austin is an adorable thirteen-year-old, who has an unfortunate problem … drooling. Cerebral palsy has a lot to do with his inability to swallow. I can’t even begin to express the social bummer this can be.

I could not understand why people just would not look past a little drool. Well...okay, maybe a lot of drool. Maybe even sometimes it hung from his lower lip like a long spider web. Sometimes it was mixed with food. Often there was a wide wet spot on his shirt just below his chin. During the winter, we had even seen this area freeze! Not a pleasant situation. This has been a difficult obstacle to overcome for Austin.

Among other obvious things, we heard, “Your child needs to use a wheelchair to get around.” Well okay, we can deal with that. Then we heard, “Your child is not going to be able to read normal sized print, drive a car, or develop at the same rate as his peers, or eat, sit, walk or talk, and all that other stuff, at the same rate as his peers.” But in time we learned to deal with all of that, too. Austin is fortunate in many ways because the other children seemed to be able to deal with all that stuff also. We’ve learned to deal with everything but “the drool”.

So, I decided to buy colored bandanas to coordinate with all his clothes. Maybe this would help. My husband and I became very selective when purchasing clothes for Austin. We would give it “the drool test”. We’d hide behind a rack of clothes in the store, and using a spray bottle from my purse, we would add a few drops of moisture to the garment --- a quick check to see how the garment might look after being worn by Austin for a few moments. White and black thin cotton always worked best. Still, Austin was asked a million times a day to swallow. “Wipe your chin Austin!” “Ooh, Austin you’re drooling…gross!” His friends at school took it upon themselves to be the drool cops. Some would go as far as to wipe his chin for him. Others, just exclaimed their disgust at his seeming lack of concern. The color coordinated bandanas didn’t seem to make a difference, even the Nike bandanas, the Tommy Hilfiger or Reebok. None of these sports icons seemed to help matters.

Correction: We apologize for an error which was made in the Fall edition of SEE/HEAR in the article, “Ultraviolet A, Blue Light and Children.” A quote from Dr. W. T. Ham on page 24 should have read, “Most authorities now believe that the near UV radiation absorbed throughout life by the lens is a contributing factor to aging and senile cataract.”
I became bitter. The younger children seemed to be more accepting of Austin’s problem. I knew that as he got older and moved up in school, this would become more of a social barrier than it had been at a younger age.

So there it began. I was on a mission, a journey, not only in the physical sense but on a spiritual quest as well. I prayed. I read. I took many long walks in the pasture. I attempted to make a deal with God. Some people might say at this point, “She’s over the top.” But I soon realized that I had trusted Him with so many other aspects of my life, but not this. I cried “Lord, this is a mountain that I cannot move. Please help!” Soon He did just that.

Our family moved to another city in the summer of ‘96. Austin was going to attend another school. This was a good thing. This also meant that I would have the opportunity to find a new team of doctors. Also, there was the hope of new horizons and fresh ideas from this change of venue.

We were referred to the Scottish Rite Hospital in Dallas, and we made an appointment with a neurologist. “What can we do about the drooling?” I asked. The doctor seemed to have a lot of experience with preadolescent children with cerebral palsy and to appreciate our concerns. After the usual barrage of questions and answers, we were handed a prescription of Artane. We were assured this may help with the drooling and sent on our way. I was thrilled. Why had I not heard of this before? I was so grateful and gave many thanks to God.

Soon after we started on the Artane, I did notice some improvement. I was very hopeful that this would make a difference for Austin. He started at a new school. The children seemed to love him right away. Even though the Artane helped somewhat, the side effects had us concerned: delayed urination, the feeling of “having to go and not being able to” became a problem. We also noticed that great care had to be taken when our son was exposed to the heat or sun for long periods of a time. He seemed to overheat even on balmy days. His face would become red and blotchy. Ultimately, the side effects continued and so did the drooling.

The summer of ‘98, I traveled to San Antonio to attend a seminar for doctors, therapists and healthcare providers. One of the topics was prevention and therapy for people who drool. I spoke to a neurologist there about Austin and our family. I shared where we were in our treatment, and what Austin was experiencing. He discussed the importance of oral simulation with different objects and how speech therapy, posture and cognitive awareness played a big part in oral control. He thought we should try another drug therapy called Robinol.

I immediately made an appointment to see our neurologist at Scottish Rite Hospital. With notes in hand and much optimism, I shared what I had learned at the seminar. The doctor was familiar with Robinol and discussed the side effects of this drug. We agreed to try it and see what happened. The new drug seemed to help at first and the drooling did appear to slow down. However, side effects were still a problem: overheating, difficulty urinating, fatigue.

Austin was in middle school by now. The children were less accepting of the drooling and his eating habits. “Yeah, Austin is a pretty cool kid most of the time; but does he drool because he’s retarded?” Austin continued to develop a strong self-image despite all this.

It broke my heart to see this happen. Friendships were being strained at best, and in some instances, friendships lost. I continued searching for “the answer”. I searched the Internet. I frequented seminars. I grilled other parents in similar situations. Often I heard, “Let me know what you find; keep us informed. Good luck.” I was constantly reminded of the desperation shared by numerous parents in similar circumstances. I prayed to God to please have mercy; please either open a door or give me a heart of acceptance.

Late in the fall of 1998, I was talking to a friend about the Scottish Rite Hospital. She asked me if I had
been to the Rainbow Clinic there? She had heard about a group of specialists who were preparing to do a clinical study on kids who cannot control saliva flow. I made an appointment.

Initially we were referred to the Scottish Rite dental clinic. Everyone was extremely caring and supportive. They told me that Austin might be a candidate for a new device that could help in controlling the saliva flow. This, I felt, was probably too good to be true. But we would try anything at this point. After a brief screening process, it was determined that Austin was indeed a candidate for this mouth appliance. We were cautiously optimistic.

An impression was taken of his bite. We learned that the appliance would fit somewhat like upper braces, and that it had a small bead attached to the back to stimulate a swallowing reflex. If it did not cause a gag reflex in Austin, this could be what we had been looking for.

We returned to the clinic weeks later to try out the mouth appliance. The moment of truth! The doctor inserted the tiny plastic and wire device, and to our relief Austin had a minimal gag response. Moments later the doctor and I noticed that he was swallowing. The drooling stopped almost immediately. I had never seen my son swallow without being told to do so. I still find myself staring from time to time in total amazement. The irony of all this is I thought I had looked everywhere for the answer, and here it was in my own backyard.

It has been about a month since Austin received his retainer. I had lunch with him at school a few days ago and was delighted to see some new and curious kids hanging around.

Today the school bus arrived to pick Austin up for school. I was scurrying about gathering all his school stuff. As he was headed out the door in his chair I quickly yelled, “Wait Austin, you forgot your bandanas.” With a full grin from ear to ear he said, “Mom, I don’t need ’em anymore.”

I want to share this story with as many people as I possibly can. The happiness on my son’s face when he said, “I don’t drool anymore,” could absolutely launch a thousand rockets to the moon. No words can express how this has made me feel, but more importantly, what this has done for Austin. God knows…He had his merciful hands all over this, and I am truly thankful.

I am also deeply grateful to the team of specialists at the Scottish Rite Hospital. Because of their countless hours of dedicated service to the children and their parents, this unforgettable opportunity is now available to many people in need.

We are going camping this Thanksgiving, and we are going to have a big campfire. Austin and I agreed we should toss those bandanas into the fire. We laughed and laughed. Austin said, “Nah…maybe Ellie the dog will want to wear them.”

Never lose sight of what you want. God bless you all. If you would like to contact us personally, we can be reached in the following ways:

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Stages in Our Lives
By Mary Zabelski, NAPVI President
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by the National Association for Parents of the Visually Impaired (NAPVI)

When my daughter, Cara, was little, I was somewhat fearful of her future, not knowing what to expect for a child who was “blind”. Sometimes, the fatalistic viewpoints of others and the continued sympathy from relatives made me feel sad. Yet my daughter never ceased to amaze me, with her enjoyment of life, her interests in the people and things around her, and her anxiousness to do what other children were doing. Just like other children!

When she was three, I enrolled her in a specialized preschool classroom for visually impaired children in our public school district. Once again, I suffered pangs of anxiety as I worried about her adapting to a new school. That first day, as she climbed up the yellow school bus steps, I felt a lump in my throat and rapidly blinked away my tears, as I kissed her goodbye. During those next two years, she made friends, caught chicken pox, learned to “pump” on the swings, and wanted a new bike with training wheels. Just like other children!

As the high school years began, I was concerned that she might not fit in or that other students might not want to be her friends. Since her mobility teacher had taught her to travel to our local high school independently, she made a neighborhood friend on the way home that very first week of school. Subsequently, she met several more girls at school who became her good friends. Although Cara and her friends were rather quiet and studious, I enjoyed hearing her laughter in the evenings as she and her friends discussed prospective or imagined boyfriends on the phone. She joined after school clubs, made National Honor Society, applied to colleges and went to senior prom. Just like many other high school students!

As college loomed ahead, I once again had doubts and fear about Cara’s future. Were we doing the right thing by encouraging her to live on campus in another state? I spent the whole summer helping her to plan her classes, organize and match her clothes, practice hairstyles, order textbooks, arrange for mobility lessons, and practice doing laundry. After freshman orientation, as my husband and I were leaving, we hugged and kissed her goodbye with tears in our eyes, knowing that she was happy, excited, and somewhat anxious about this new stage in her life. Just like the other students! Just like other parents!

The return of cancer after college, her successful recovery, her athletic feats, Paralympic medals in cycling, law school graduation - these were more stages in her life and mine.

Last week, at the age of twenty-eight, Cara got married. She and Spencer are dreaming and planning their future together. Just like many other young men and women!

As I look back on all of the stages that we have passed through, one thing really stands out in my mind: Cara was a child, a teenager, a young woman just like other persons are children, teens and young adults. The issues and stages that she passed through are common to us all.

As parents, we had some decisions to make. Even though it may be easier to “do” it ourselves, rather than to allow our children to struggle at a task, in the long run, the hard way is best. As Cara mastered chores, sports, travel routes, she became more confident in her own abilities. She had opportunities to be like the other children - to take on responsibilities, to participate in normal social activities and games, and to successfully accomplish small tasks on a regular basis when she was growing up. Now she feels good about herself and has confidence in new situations.
I encourage you to look at your child as a person first, with individual talents, skills, personality traits and abilities. Give your child responsibilities, encourage his or her independence, and spend quality time together. The blindness, visual impairment or other disabilities are a permanent inconvenience, of course, but are incidental to just being your child, with his or her own unique, special qualities. Just like any other person’s child!

**Advocacy Tips and Techniques:**

**Ideas by and from Parents and Those Supporting Parents and Children**

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Information and Consulting on Special Education Issues

<http://members.aol.com/pepofwi>

Editors note: Anyone who has ever attended ARD/IEP meetings knows how stressful they can become. These meetings can quickly get out of control if you haven’t done your homework. Even parents who are also in the field of special education, have noted that ARD/IEP meetings are very different when it is for their own child. These parents know their rights, the process, the “right way” to participate; but it can all go out the window with one comment about their child from a professional. Getting a handle on your emotions will make the negotiations more effective. One strategy I encourage parents to use is to schedule informal meetings with their child’s teachers and therapists to discuss concerns and review any assessments BEFORE the ARD/IEP meeting. This allows all parties to know ahead of time any issues that need to be addressed. No one likes to be broad-sided. Besides, most of us need time to process and investigate options in order to have an appropriate response. Routine contact between school and home through communication notebooks, phone calls, videotapes, home visits, and classroom visits can prevent the buildup of misunderstandings. Frequent discussions between parents and staff clarifies expectations and takes the edge off the formality of the ARD/IEP meeting itself. The following article gives practical strategies for making your next ARD/IEP meeting successful instead of stressful.

**BRING A BUDDY**

A recent PEP-WI survey revealed that only about 18 percent of parents are bringing someone (friend, spouse, neighbor, relative, etc.) with them when they go to IEP meetings. From experience, we know that when the parent brings someone to the meeting who is knowledgeable about the child or who has special expertise, the tenor of the meeting becomes more mutually collaborative, more mutually respectful, and frequently more productive. Children’s needs remain the focus; all members of the IEP team are more likely to work together to create solutions. You can improve the quality and effectiveness of your child’s IEP Team meetings by bringing a buddy. Here are some ideas to help:

a. Pair up with another child in your child’s special education program. You go to their meetings, they come to your meetings.

b. Make a friend at a parent support group (like CHADD, ARC, Family2Family, etc.). Agree to buddy-up at meetings. Better yet, attend a PEP-WI (Partners Resource Network) training or two together!

c. IEP Meetings must be scheduled at mutually agreeable times and locations. Recommend times and locations where you and your spouse or significant other can both attend. You have the right to a meeting at a mutually agreeable time and place.

d. If your child receives physical or occupational therapy or counseling outside of school, invite that service provider to attend the meeting. Use conference calling if needed.
e. Ask your child’s aunt, uncle, cousin, grandparent or other relative, who has a special understanding of your child, to attend with you.

f. Consider asking a sibling to attend. He or she “knows” your child in unique ways.

g. Invite last year’s teacher, aide, or therapist to come.

h. Offer to share YOUR services going to someone else’s meeting with them and have them come with YOU.

IF YOU THINK THE MEETING IS GOING TO BE STRESSFUL

If you think that your meeting with the IEP Team is going to be stressful, try these suggestions:

a. Start by talking about some areas you know you all will agree with. Find common ground. Example: “I know you have found Jon’s behavior difficult to control at times. We have had similar experiences at home.”

b. Use AND instead of using the word BUT. “But” acts like an automatic switch inside listeners’ minds. It “switches off” the first part of the sentence or message. Example: “We need a plan to get my daughter’s behavior under control AND we need to keep in mind that she also needs to experience academic success in the general education classroom.”

c. Avoid using absolutes: “You always…, We never…”

d. Use positives to help move the conversation along. Example: “What if we tried…?” “Would you be willing to try this?” “It sounds like it might be better if we…” “Have we thought about this?”

e. Allow your listeners to correct any possible misunderstandings you may have gotten. “Can you help me understand why you…?” “Tell me again why we are…” “Oh, okay, that clarifies that for me a lot.”

f. Don’t take a position. Deal with a need. Example: “My son needs to feel successful at school. How can we make that occur?”

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Inalienable Rights

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

Working with parents is one of my joys in life so I am puzzled, at times, when I am asked to speak to teachers and other professionals on “How to Work with Parents.” Over the years I have collected tips and techniques from a variety of sources, the most practical and enlightening coming from parents. I have found that during interactions between parents and professional that attitudes can say more than words. Who we are, our assumptions, values, and experiences, become a part of our message whether or not it is intentional. I recently discovered this piece written by Dr. Leo Buscaglia in the The Disabled and Their Parents: A Counseling Challenge published by Charles B. Slack, Inc. in 1975. The late Dr. Leo Buscaglia, a well-known, best-selling author, was in the field of special education for over 40 years and he wrote this piece over 20 years ago. I think it still holds true today.

BUSCAGLIA’S BASIC RIGHTS OF THE FAMILY

The basic rights of the family having a child with special needs might include, as a start the following:
The right to sound medical knowledge regarding their child's physical or mental problem.

The right to some form of continual re-evaluation of their child at definite, periodic intervals and a thorough, lucid explanation of the results of the findings.

The right to some helpful, relevant, and specific information as to their role in meeting their child's special physical and emotional needs.

The right to some knowledge of the educational opportunities for a child such as theirs and what will be required for later admission for additional formal schooling.

The right to knowledge of the community resources available for assistance in meeting the family needs: intellectual, emotional, and financial.

The right to knowledge of the rehabilitation services in the community and the resources available through them.

The right to some hope, reassurance, and human consideration as they meet the challenge of raising a child with special needs.

The right to some hope in seeing their child's potentials instead of forever concentrating upon his imperfections.

The right to good reading material to help them acquire as much relevant information as possible.

The right to some interaction with other parents who have children with disabilities.

The right to actualize their personal right as growing, unique individuals, apart from their children.

**Orientation and Mobility: Infants and Beyond**

By Diane Barnes, Certified Orientation & Mobility Specialist

Region 13 Education Service Center, Austin, Texas

**INTRODUCTION**

As part of the Functional Vision Evaluation/Learning Media Assessment, VI teachers are required to determine if an evaluation by a Certified Orientation and Mobility (O&M) Specialist is needed. Specific skill areas which may impact a child’s present and/or future travel skills should be assessed. These skills relate to safe and efficient travel. Instruction in these areas may influence the child’s developmental growth, which in turn may impact the level of travel skills he or she may develop. For example, will he develop skills that will allow him to travel only in familiar areas, with extensive orientation, or in very structured settings? Or can he be independent in both familiar and unfamiliar areas?

VI teachers focus on skills which impact the child’s functioning in the home and school environment. These skill areas include, but are not limited to: visual efficiency, motor planning, concept development, environmental awareness, object identification and interest, and communication. They employ a variety of strategies to assess these vision skills with infants and young children such as presenting an object or toy at close range, from a specific side, or by moving it. They generally use toys or objects that are brightly colored, have auditory feedback and light sources, or which have been adapted with contrasts. This also helps to encourage optimum participation and interaction by the child during the assessment.

When considering the child's travel skills, the home environment is generally the most controllable environment. Once the child moves into the school environment, the environment can continue to be controlled to some
extent. For instance a student might be given additional time to travel from place to place, curbs or steps can be painted brightly, highly contrasting colors used between walls and flooring, and so forth. However, beyond the home and school settings, the child’s travel environment is less accommodating and more unpredictable. It is important to address travel skills in both familiar and unfamiliar environments or environments and situations that are less than ideal. On-going exposure to and guidance in handling these types of situations plays a significant role in helping the child acquire the skills needed for travel in both familiar and unfamiliar environments. In addition, instruction may also impact whether she will be able to travel without the use of a cane, needs to use a cane all the time or only in certain situations, knows when the cane is needed, and can interpret and properly respond to cane feedback.

ACTIVITIES

Listed below are some O&M related activities that address these critical skill areas. These are also activities which can assist the VI teacher in determining the need for an O&M referral.

- Place an item to the right of the child, and have her to reach for it with her left hand; reverse the process. Place item at midline and have child reach for it with alternating hands. This helps develop the ability to cross midline, extend the arm, reach for and contact an object; all of which are critical to success in using a cane.

- Place pillows on the floor and have child sit and/or stand on them as she reaches for items placed on the couch. This works on coordination and balance necessary for negotiating steps, curbs, wheelchair ramps, or broken sidewalks.

- Occasionally change the location of an object from where the child expects an item to be located. For example, a favorite toy changes from being stored on the left on the first shelf to being stored on the right or on the next shelf up. A toy basket moves from a spot by the bedroom door to the closet. These types of situations teach such skills as problem solving, route planning, visual searching, tolerance/patience, and soliciting aid. Learning these kinds of skills may allow a child to develop the ability to progress beyond being a “route traveler.”

- Start with completely covering/concealing a familiar item, and have the child to try to identify it as you reveal it little by little. This builds the ability to interpret part, whole, and “clutter.” She will need this ability for example, so she can identify a newspaper stand partially obscured by a trash can from a distance. It also helps develop patience and tolerance, problem solving, vision efficiency, and the ability to identify landmarks.

- Align floor mats, crumbled blankets and towels, and small rugs turned up on one corner in a path on the floor and have the child negotiate these items as she comes to you. This helps to develop a tolerance of terrain changes and works on motor planning and control.

- Provide instructions to your child with music in the background, the window open, or the washing machine or vacuum cleaner going. This helps teach him not be startled by a trash can knocked over by a dog as he is preparing to cross the street or become distracted by kids opening and closing lockers as he walks down the hall.

CONCLUSION

If the child demonstrates difficulty at any point with any of these activities, it is probably an indication that the VI teacher needs to make a referral for an O&M assessment. In most instances the VI teacher can ask herself a simple question: “Is the child visually impaired and moving (scooting, crawling, pulling up on furniture,
If the answer to this question is "yes", then the VI teacher should give her O&M Instructor a call to discuss the need for a referral. Determining the O&M needs of children with visual impairments has to be an on-going assessment process. This requires a strong collaborative relationship between the vision teacher and a certified O&M Instructor. Through this collaborative process, the vision teacher should be able to determine when it is necessary for the O&M Instructor to provide direct intervention with the child.

**Information for Parents About Assessment**

Marnee Loftin, School Psychologist
Texas School for the Blind & Visually Impaired

*Editor’s note: Thanks to Marnee for allowing us to reprint this excerpt from her book, Assessment of Students with Visual Impairments that will be published this summer by the TSBVI Curriculum Department.*

Assessment is a critical aspect of planning an educational program for a child. Yet most parents of children with visual impairments will find this process to be one of the most difficult and stressful ones that they encounter. Any parent who has experienced the development of an IEP will have at least one horror story regarding problems associated with assessment of their child. Assessment is something that occurs regularly, and will often form a basis for long-term decisions about their child. It is important that parents develop their own skills in understanding the process and providing relevant information to the person who is coordinating/completing the assessment.

**WHAT KIND OF ASSESSMENT WILL BE COMPLETED?**

There are a multitude of laws and state regulations that govern the types of assessments that are likely to be given. However, the entire process focuses upon looking at strengths and needs in the following areas:

- Language
- Physical
- Vision /Hearing
- Health History
- Sociological
- Emotional /Behavioral
- Intelligence and Adaptive Behavior
- Academic Performance
- Assistive Technology

The new IDEA gives parents and school personnel a great deal more freedom in planning which areas actually need to be formally assessed. Every three years, the ARD Committee will meet and make a determination regarding the need for assessment in each of these areas. The ARD Committee may make the decision that no new assessment needs to be done, or that any one of these areas needs additional assessment.

Making the decision about the need for assessment is often difficult for members of the ARD Committee. Parents are often hesitant to agree to testing/retesting because of the concern that additional disabilities will be identified incorrectly. In the process of making this decision, it is important that parents have clear understanding of the possible benefits that might be seen from appropriate assessment. Certainly if problems in teaming are evident, it is important that additional assessment be completed to determine what other strategies might be useful to improve learning.
WHAT DOES THE ASSESSMENT PERSON KNOW ABOUT VISUAL IMPAIRMENT?

Most assessments completed in a public school will be completed by an educational diagnostician or by a psychologist. Both of these professionals have considerable training in assessment of children, but neither is likely to have a base of knowledge regarding visual impairment. Legally they are required to consult with the vision teacher and make appropriate modifications, but it is important that you as a parent assist them in understanding your child’s visual impairments before the assessment. Be certain that you have written information that gives specific details about the visual condition, prognosis, and implications in a classroom. The teacher of the visually impaired will also give assessment professionals some of this information. As a parent, however, you may have access to slightly different kinds of information that you have obtained directly from physicians and other specialists. Remember that the assessment professionals are motivated to do the best possible job of assessing your child, but will likely have very little information about visual impairment or the multitude of implications of these conditions.

HOW CAN THIS INFORMATION BE GIVEN?

This article, as well as a variety of excellent textbooks, will give specific information about helpful techniques as well as appropriate assessment instruments that will be of benefit to the diagnostician or psychologist. However, being the parent, you will likely be the best source of basic information about the specific visual condition, as well as early development patterns of your child. Parents who have been involved in the IEP development process for a number of years have often developed a brief summary of their child that explains the visual condition, the etiology, developmental milestones, and techniques that they use to decrease anxiety for their child. This is information that will be of value to each assessment professional that works with your child over their school career. Many parents report that having a prepared package of information decreases the stress and frustration of having to repeat this information each time that a new assessment professional works with your child.

An assessment professional will have complete access to all of the educational records on your child. These records will be reviewed to gain an impression of the types of progress made over the years. It is also helpful if you have some information available that shows the progress that you have seen at home. This may be videotapes of your child engaged in daily living skills activities, a portfolio of “special” work that you have saved over the years or anecdotal notes on developmental milestones. All of this information gives the assessment professional valuable insight about performance in a different environment. Although this information can certainly be reported verbally, showing specific examples is always helpful.

WHAT IS THE REASON FOR ASSESSMENT?

The reason for any assessment is to determine the strengths and needs of an individual child. With the recent changes in IDEA, assessments are not completed simply because “it is time for the three year assessments”. Assessments now are completed because the members of the ARD Committee feel that there is a need for additional information to assist in developing or modifying the individual educational plan. Most frequently these needs center around exploring the difficulties that a child may be having in learning a specific concept or group of concepts. An occupational therapy evaluation may be requested because the child is having difficulty in mastering Braille, a speech and language evaluation because the child is having difficulty with auditory processing that is slowing down learning.

New evaluations will also be requested because new techniques are available to improve functioning that may not have been available previously. These frequently occur in the areas of low vision evaluations and technology evaluations. Not only are these fields constantly developing and changing, the increased maturity and development of your child may open new options for them.
The final reason for assessment, and the one most often feared by a parent, is an assessment requested to explore the possibility of an additional disability. This is difficult for parents especially if that additional disability may be significantly impacting learning in a number of areas.

**WHAT IS THE ROLE OF THE PARENT IN ASSESSMENT?**

Regardless of the age of the child, you have two major responsibilities in the area of assessment. The first is to actively participate in making decisions about which types of information are needed. The second is to assist the assessment professional in obtaining the most comprehensive information about your child, the visual condition, and the changes that you have seen over the years in your child’s functioning.

It is extremely helpful to provide the assessment professional with specific questions or concerns that you may have about your child. For example, do you feel that the development of daily living skills are not progressing as rapidly as you had hoped? Are you pleased about the way your child interacts with adults, but concerned about social interactions with peers? Do you see signs of increasing social withdrawal as your child becomes older? Specific questions can assist in planning the assessment not only in terms of types of evaluations requested, but also in the selection of a specific test to be used.

**WHAT ARE THE ADVANTAGES OF AN ASSESSMENT?**

It is often difficult for parents to see the advantages of formalized assessment in addition to that conducted in the classroom. When the need for additional assessments is discussed, parents often are not sure how they feel about the issue. The assessments are sometimes seen as a way to add undesired additional disabilities and part of a discriminatory process that further increases the isolation of their child. It is important that teams make a realistic appraisal of the advantages of the assessment process.

Although parents often fear the possibility of the identification of additional disabilities, a more critical fear is that additional disabilities or specific needs will NOT be identified. Years of experience in the field of special education indicate that problems that are most frequently identified as being the result of poor motivation, lack of interest, or so forth on the part of the child, need to be further explored. Certainly this will be the case with some children, but in virtually all cases different instructional strategies or procedures will result in an increase in rates of learning. The key to finding these strategies is quality assessment data that will identify specific strengths and needs as well as the presence of additional disabilities. Quality assessment should result in instructional changes. Whether these changes are based upon an objective statement of strengths and needs or additional disabilities, the ultimate outcome should be better instruction for your child. Assessment should not be an evil to be avoided but an integral part of your child’s instructional program. Your responsibility as a parent is to ensure as much as possible that it is a quality assessment.

**WHAT WOULD BE CONSIDERED A QUALITY ASSESSMENT?**

A quality assessment would be considered one that meets the following criteria:

- The individual completing the assessment has received information about the visual condition as well as the educational implications.
- Modifications have been made in the assessment process which are consistent with those specified in the individual educational plan.
- The report identifies specific strengths and needs of the student.
- Recommendations for addition of other disabilities are presented in a manner that clearly states the methods used to determine the presence of this disability.
Educational implications of additional disability or identified need are clearly stated.

All recommendations are made to ensure continued growth toward independence for your child.

Recommendations should not focus upon simply increasing supports without a specific plan for eventually decreasing these supports.

The report is written in a manner that answers the questions you presented for consideration and is understandable to you as a parent.

WHAT ARE THE MOST COMMON ASSESSMENT PROBLEMS?

Undoubtedly the most common problem is to underestimate the difficulties associated with low vision. If a child has no useable vision, assessment professionals seem to be extremely cautious regarding adaptation. If acuity appears to be good, modifications are often inappropriate. For example, the impact of fatigue, lighting conditions, figure-ground problems, and field losses are often underestimated. As such, tests are given and implications drawn that are not valid. For example, a child with low vision may be able to complete the Block Design portions of the WISC-III with little difficulty. However, that does not mean that the fine visual discriminations necessary on other portions of the WISC-III can also be made. It is important that the assessment professional understand that the assessment of a child with low vision is likely to be one of the most complex tasks that can be undertaken.

The other common difficulty is associated with the modifications that are made in the testing process. Both inadequate as well as excessive modifications can make assessments less meaningful. The goal of all involved in the assessment process is to determine if modifications can be made in a meaningful manner and to ensure that such modifications are made appropriately.

Your child is legally entitled to each of the modifications that are listed in the IEP. For example, if the IEP requires that materials be presented in an auditory format, testing should occur in an auditory format. However, you should be aware that all tests cannot be modified to reflect the recommended modifications. To do so would mean that the tests would be meaningless. Reading questions on an audiotape for a year-end test of government would likely be an appropriate modification if materials had been presented on tape for the majority of the class. However, reading a test to determine a reading level would be a meaningless modification, and it would invalidate the purpose of the test. For many parents one of their great difficulties is determining when modifications should be demanded in the testing process and when exemptions are the most appropriate. The most important criteria to consider would be the intended purpose of the test.

CONCLUSION

Parents have always had a critical role to play in the assessment process. With the implementation of the new IDEA, the law requires that parents play a greater role in this critical aspect of program planning. All of the decisions your team makes about your child’s program rest on the quality of the assessment that is done. Begin now, long before your next IEP meeting, to think about the quality of assessment that has been done on your child. Do you have copies or have you read through all the assessment information? Do you have information collected to share? Do you understand what the tests indicate in terms of your child’s strengths and needs? If not, have you scheduled appointments to meet with the team members who can explain the assessment data? Do you think there may be other areas where new assessment information should be gathered? Have you discussed with your child’s teacher or diagnostician what types of testing might be needed to address this concern? It never too soon to begin to prepare for your role in the assessment of your child with disabilities.
Bringing It All Back Home: Family-Driven Assessment and Intervention for Children who are Deafblind

By Dr. Charity Rowland, Co-Director, Center on Self-Determination
Oregon Institute on Disability and Development, Oregon Health Sciences University

Bringing It All Back Home is a project at the Oregon Health Sciences University's Center on Self-Determination, a program of the Oregon Institute on Disability and Development. The project is funded by the U.S. Department of Education. The goal of the project is to develop a set of materials designed by and for parents of children who are deafblind to evaluate their children, to establish intervention priorities for home and community, and to ensure successful transitions from one school or classroom to another. The project targets 3-12 year old children who are deafblind and involves parents as partners in model and product development and in field-testing efforts.

CURRENT ACTIVITIES

A team of parent consultants from Oregon and Washington is currently working on assessment and evaluation issues. The team has provided input into these issues and we are also collecting input through the World Wide Web. The team is seeking input on these issues from other parents of children who are deafblind. Our web site address is <http://www.ohsu.edu/selfdetermination/index.shtml>.

This web page describes the project and has a link to a form for submitting the ideas of parents on the assessment and evaluation of their children. The form is provided in English and Spanish. Input received through the web site will be reviewed by our parent consultants and by project staff. If you are a parent, we are interested in your ideas on the assessment and evaluation of your child. Also, if you know other parents who might like to provide input, please pass this information along to them.

PARENT OPINIONS ON ASSESSMENT AND EVALUATION

So far, the major opinions that have been expressed by parents regarding assessment and evaluation are summarized below. These ideas will be integral to the development of assessment instruments which the parent consultants are working on now.

- Important behavioral domains to assess are: communication skills, perceptual capability, tactile defensiveness, tactual learning, social development, gross/fine motor development, and cognitive development.

- Specific information that should be gathered about the child includes: preferences, effective rewards, habits and routines (sleeping, feeding, etc.), recent progress, community-based experiences, ability to adapt to changes and transitions, motivation/initiative to explore the environment, sources of frustration and how the child expresses frustration, health status, home life, and responses to music/rhythm/voice/movement.

- The role of parents in the assessment/evaluation process involves: providing general information about deafblindness, providing documentation of the child's learning, sharing goals for the child, informing the team of the child's progress, and helping the team to recognize the child's skills.

- Suggested formats/styles for evaluation include: developing a formal parent report (just like professional members on the educational team), developing guidelines for categorizing behavior so parents can present their information in an organized way, use of anecdotal information to highlight special skills, starting with the concept of the overall goal being to increase the child's independence, including an executive summary of the child's skills and behaviors, use of videotapes of the child, and use of life-print memory/picture books.
• Appropriate contexts for evaluation include: the home (especially for younger children), the community, and unfamiliar as well as familiar environments.

• Measurement ideas include: conducting several administrations of assessments within a few months, establishing a baseline and then a standardized form to collect supportive data over time, providing a scale that is not age-based or IQ-based.

FUTURE ACTIVITIES

In future years, we will be seeking input on setting intervention priorities and transition issues. Another avenue for family involvement in this project will occur during our field-testing phase, when we will be seeking families to use and evaluate the materials developed through the project. When we are ready for field-testing we will contact the coordinator of your state deafblind project, and will also make an announcement on our web page. We also welcome your input into other aspects of the project at any time. You may contact project staff at:

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To Be VI or Not?

By Joyce Rodriguez, Vision Consultant
Region 2 Education Service Center, Corpus Christi, Texas
Reprinted with permission from VI Newsletter Fall, 1999

Editor’s note: The original article was an e-mail response to questions submitted to Marty Murrell, Education Specialist at Texas Education Agency by Joyce Rodriguez, Vision Consultant at Region 2 Education Service Center. It is part of Marty’s role to assist districts and staff with questions about services for students with visual impairments. The original response which appeared in the Fall 1999 VI Newsletter has been updated by Marty for inclusion in SEE/HEAR.

QUESTION:

I just need some basic information about establishing initial eligibility for a visual impairment. When a student is initially referred for suspected visual impairment, is an eye specialist’s report stating that the student has a serious vision loss after correction needed BEFORE they do a functional vision evaluation? I know eligibility is based on the combination of the two pieces of information, but doesn’t the eye exam have to state serious vision loss even after correction?

In other words, if the eye exam says the student does NOT have a serious vision loss after correction, then should the referral come to a halt at that point? Or would the VI person still be obligated to evaluate the student (per ARD committee recommendation)?

RESPONSE:

The answer would depend on whether or not the district determines that an evaluation for special education is needed.
The district determines an evaluation is needed for special education

If the child is referred for evaluation for special education because of a suspected visual impairment, and the district agrees to evaluate, there are two guiding principals related to your question:

First, eligibility is an ARD committee decision, and secondly, federal regulations state that no single procedure is used as the sole criterion for determining whether a child is a child with a disability.

The first step of the evaluation is to obtain the eye doctor report. This should be provided at no cost to the parent. The information from that evaluation should serve as a guide for the functional vision evaluation (FVE) and learning media assessment (LMA). Information from both should guide the rest of the evaluation process.

If the eye report comes back saying there is not a serious impairment, there still must be the FVE/LMA and the rest of the evaluation. These evaluations will either support the doctor’s findings or challenge them. If the FVE/LMA indicates there really is a serious visual problem, then there should be discussion with the doctor to try to determine why there is a difference of opinion.

(In Texas, when the vision rules were first developed, the intent was to ensure an eye doctor did not have the final say about educational issues. That is one reason the eligibility criteria does not depend solely on acuities. Remember, the doctor’s evaluation reflects how a child sees in a very atypical setting. Sometimes the doctor has limited expertise with hard-to-test children, may have checked the wrong box by accident, or may not realize the significance of his choice.)

Sometimes, with technical assistance from the vision specialist, the doctor will be willing to correct mistakes, or restate conclusions based on the additional information from the district. If the doctor does not change his opinion, but the FVE/LMA indicates there is a serious problem and the comprehensive evaluation indicates there is an education need because of it, the district should seek another eye doctor evaluation. As a last resort, if there is disagreement, but the vision teacher and the rest of ARD committee feel very strongly that there is a visual impairment resulting in educational need, the ARD committee may go ahead and qualify the student. There should be detailed documentation supporting this decision. (Kind of an unwritten Method II for VI!) One would not expect this option to be used very frequently.

The district determines an evaluation for special education is not needed

The district could refuse to evaluate under the following conditions:

√ If the parent brings in an eye report and asks for an assessment for special education because of a suspected visual impairment,

√ and the information from the eye report does not indicate a severe visual loss after correction,

√ and, based on classroom observations, academic performance, and other relevant information, the district does not believe that there is justification for further assessment,

√ then the district could refuse to evaluate.

If this is the case, the district must give the parent written notice of refusal to evaluate. The parents must also receive a full explanation of their procedural safeguards. (See Sample Forms for the Child-Centered Education Process on the TEA website <http://www.tea.state.tx.us/special.ed/spedpub.html>.) This will give the parents documentation that their request was denied, so that they can request mediation, file a complaint, or go to hearing, if they so choose.
Education Protocol for Cornelia de Lange Syndrome
Mary T. Morse, Ph.D., Special Education Consultant, Pembroke, New Hampshire

Editor’s note: Recently I visited the Cornelia de Lange Foundation, Inc. website in search of information for a classroom teacher. I came across this wonderful article, one of the many interesting things available at this site. I would encourage families and professionals who want to learn more about CdLS to visit this site if they haven’t discovered it already. There web address is <http://cdlsoutreach.org>. My thanks to CdLS Foundation for giving their permission to reprint this article for our readers.

Cornelia de Lange Syndrome (CdLS) has great variability in its manifestation, from those individuals who are visually recognizable as having CdLS to those who, to the uninitiated observer, display no unusual physical and/or behavioral characteristics. A common characteristic, however, is that numerous infants, preschool and school-age children with CdLS have a range of significant medical and health issues that consume parental physical, emotional and financial energy and the attention of numerous professional disciplines. Many children diagnosed with CdLS also present another set of concerns, namely in the area of communication and behavior. Planning and providing appropriate quality educational services for children who have CdLS must consider the influence and interplay of both sets of issues and concerns.

Education is a cultural activity with schools charged to prepare children for the life they will lead in the culture they will live. Education can be thought of as the other side of the coin from the medical and health-related issues and, as such, needs to be addressed simultaneously.

PHYSICAL, ENVIRONMENTAL, INSTRUCTIONAL & SOCIAL CONSIDERATIONS

Factors to Consider

Factors to consider in educational planning include the child’s medical and health status, stamina, ability to manage sensory-motor demands, levels of arousal, communicative status, need for structure and organization, relevant goals and objectives, motivating and understandable activities, and appropriate adaptations. Moreover, the child with CdLS needs to be an equal partner in interactive and satisfying social experiences. Social equality rests, in part, on helping oneself as much as possible, communication abilities, contributions to others, and shared experiences.

1. Medical-Health Related Issues: There is a critical need for family, medical-health personnel and school staff to communicate with each other around issues affecting health. School staff needs to be sensitive to those periods when there is a flare-up of gastro-esophageal reflux. Staff also should be informed of food allergies and strictly adhere to dietary limitations. Lastly, staff needs to distinguish between those periods of fidgeting and non-attentiveness due to discomfort and pain vs. those periods when the behaviors are due to other causes. The situation, of course, is easier to understand and manage if the student has expressive language.

2. Communication: Any discourse on education must involve the discussion of communication. We cannot transmit or receive information unless we communicate. Children with CdLS are at risk for delayed or absent speech, difficulty in understanding the subtle nuances and pragmatics of language and auditory sensitivity to a barrage of speech sounds. Speech is very difficult for many individuals with CdLS due to oral-motor apraxia. These children do not choose not to talk but find the coordination and production of the motor actions extraordinarily difficult – especially under typical school-like demand situations.

a. While speech may be the ultimate goal for those children who currently do not talk or find
talking difficult, they need a way to express themselves now so they may be more active participants in the educational process. There are a variety of educational techniques that can be employed to help these children communicate right now while they simultaneously work on the higher goals of speech production.

b. Speech may not be a realistic goal for some children with CdLS. There are, however, a great many other educational techniques that can be employed for very effective communication. These techniques are very reliable regardless of the country, culture and/or the education program.

c. Signing may/may not be an effective route for some children due to such receptive difficulties as (1) poor visual attention, (2) a visual handicap and/or (3) the transient/spatial/speed nature of sign. Expressive difficulties may be difficult due to factors such as (1) upper limb malformations, (2) dyspraxia (difficulty in performing smooth, rhythmical and sequential hand motions), (3) memory for motor movements and so forth.

d. Although most children with CdLS are said to have visual-perceptual strengths, this does not necessarily mean they understand all forms of visual stimuli. Visual regard for two-dimensional representation (pictures, line drawings, photographs, print) does not automatically mean there is understanding of this form of symbolic representation. An assessment of such understanding is highly recommended.

e. Technology provides many options for augmenting communication and has been a major boon for persons who have disabilities. However, computers and other high tech devices are not the answer for every child. There are basic skills that must be learned in order to use this technology effectively as communication and learning devises. Students need both a basic understanding of the communication process and of the concrete world of objects before they are able to manage the abstract world of symbols.

f. In general, children who have multiple disabilities are at very high risk for missing out on numerous incidental learning experiences that typical children pick up so easily. These types of experiences center around the concrete world and bring together the visual, hearing, touch, doing foundation necessary to manage the abstract world of symbols.

3. **Vision:** Myopia (near sighted), amblyopia (lazy eye affecting depth perception), chronic conjunctivitis-appearing eyes, and dry eye syndrome (making the eyes feel as if they have sand in them), photophobia (light sensitivity) and ptosis (droopy eye lids) are common visual problems. Students with these symptoms may need drops for lubricating their eyes and eye washes done in school. They also may need (1) preferential seating close to the blackboard, (2) assigned seating facing away from the windows or other sources of glare due to their light sensitivity, (3) adapted but non-glare lighting to highlight the specific work area, (4) special printed materials if vision is limited even with corrective lenses, and (5) alternating work requiring fine visual functional skills from work requiring less fine visual performance in order to reduce fatigue. Fatigue may result from the need to constantly shift head positions to accommodate to the ptosis. Teachers should know if glasses have been prescribed for the student and what is the recommended pattern for wearing them. Sometimes glasses are prescribed for specific activities. If the student has use of only one eye, it may be helpful to know if safety glasses should be worn during certain activities. Some students will have a documented visual handicap and will require the services of a trained teacher of the visually impaired.

4. **Hearing:** Students may have a documented hearing loss or fluctuating hearing requiring close communication and coordination with the pediatrician and with the audiologist. Such students may require use of hearing aids, a FM system and/or preferential seating near the teacher. If either hearing
aids or a FM system are prescribed, staff should be aware of how to adjust the settings, how to work with the ear molds, and the best times to use the equipment. Other children with CdLS may have delayed responses to auditory stimuli which require that they be given time to process the auditory information and plan their responses. Some students will require the services of a trained teacher of the hearing impaired.

5. **Vision & Hearing:** Some students with CdLS have both a vision and a hearing impairment. These students are considered deafblind and require very specialized teaching. Deafblindness is not a simple “one plus one equals two” but rather, presents significant risks in learning due to the impact of the dual sensory disability on the development of a language system. Teaching techniques oriented toward children who are visually handicapped rely on intact hearing and touch. Teaching techniques oriented toward children who are hearing impaired rely on vision. When neither sensory modality is intact or reliable, alternative communication techniques need to be utilized. Moreover, the efficiency in which a deafblind individual is able to use their residual vision and hearing is highly influenced by stress, health, medications, fatigue, background noise/visual clutter, size/distance/plane of presentation/etc. of the visual stimulus, speed of presentation, competing sensory stimuli and many, many other factors interwoven with each other. All children who have combined visual and auditory disabilities require the services of a trained teacher of the deafblind.

6. **Visual & Auditory Processing:** Many children who have both visual and auditory disabilities have associated problems in processing and understanding the visual and auditory messages. Cortical visual processing problems are the biggest single cause of visual handicaps in the United States. In most of these situations, central auditory processing problems also exist. We do not, at this time, have enough data to provide information on the incidence of these cortical processing problems with individuals who have CdLS. However, prematurity, a history of difficult birth and neonatal period, and/or anoxia, place a child at risk.

**A FEW STRATEGIES**

1. A well-organized routine and predictable, calm, organized environments seem most conducive for students with CdLS. Schedule and calendar systems via objects, pictures, line drawings and/or words can help the student anticipate and prepare for changes in the schedule. Such schedules should be in the format the student most easily understands.

2. Allowing time for the student to process, plan and implement a response to sensory information is essential. The number and pacing of activities may have to be individualized – especially for those students who have limited stamina, endurance and ability to control their own state of arousal. Take advantage of the visual strengths the student may have by orally giving the directions, then visually present the questions and/or demonstrate the method, and end by giving the oral directions again. Time constraints potentially may add to the stress, which, in turn, will reduce processing time further.

3. Many of the students perform better with concrete learning experiences. For example, applying math principles by going into the community to shop for needed items involves planning, reading, mobility, safety, social etiquette and so forth.

4. If handwriting is laborious, investigate the advantages of computer use for the student.

5. For those students in academic programs, some may need rest breaks to reduce their level of arousal. Simultaneously, many need specific tutoring or pre-teaching, in a resource room, to deal with subjects they find difficult in the mainstream.

6. Some of the students have a difficult time taking the initiative and making their needs known. They
may find casual, recreational times with typical peers difficult because of the unpredictable nature of social events and anxiety in unfamiliar situations with unknown outcomes. To promote positive social-emotional growth in these students, determine the appropriateness of the student becoming a big sister/brother to a younger child and/or social skills training in a small group of socially-similar students.

7. Many students with CdLS, who also have significant additional disabilities are in inclusive environments. Most often these experiences are not really social because there is very little INTERAction. However, the students profit best from such techniques as A Circle of Friends and from structured and facilitated interactions with peers.

Editor’s note: Below is some additional information on CdLS that is available on the CdLS website.

FAMILY ISSUES

Whether an individual is diagnosed at birth, or at age two, five or twenty, receiving a diagnosis of CdLS can be overwhelming. A lifelong process of challenging and re-challenging feelings, thoughts, actions and beliefs may begin. There will be sadness, but there will also be joy. There will also be many decisions to be made, but they do not need to be made in isolation. There are many families and professionals ready to offer information, support and encouragement to people who request it.

Families may struggle to accept the diagnosis of Cornelia de Lange Syndrome. Shock, anger, denial, guilt, and sadness are common early responses. Most families adjust to their new situation, but protracted grief or depression in a family member should be treated. In addition to the initial adjustment, intermittent stresses throughout the life of the child may temporarily destabilize a family. The primary care providers should periodically inquire about family adjustment and continue to provide emotional support for the family.

Children may qualify for special services such as CAP/MR (Community Assistance Program for the Mentally Retarded) through the division of developmental disabilities at their local mental health center. Most children should be eligible for medicaid (independent of parents’ income) which provides prescription coverage as well as physical, occupational and speech therapy. In addition, respite care should be suggested in cases where the caretaking burden is high. The Association of Retarded Citizens often has a respite program and also provides support for families.

BEHAVIOR

Although many children with CdLS have no significant behavioral problems, there are some conditions, which makes self-injurious behavior more likely to occur: pain, discomfort, frustration or dismay. The typical young person with CdLS may be described as hypersensitive and dysrhythmic. He/she may be hypersensitive in that he/she may have strong reactions to ordinary stimuli and these reactions may continue long after the stimulus is gone. He/she is sometimes dysrhythmic, that is having irregular patterns of behavior in the areas of eating, sleeping and emotional response.

The lack of sensitivity to pain and/or heightened sensitivity to touch suggests some individuals may have neurological impairment. They may also be prone to behavioral problems such as hyperactivity, short attention span, and oppositional or repetitive behavior.

PSYCHIATRIC EVALUATION

Many of ordinary problems that children have can be dealt with by a pediatrician who has some developmental or behavioral experience. These would be minor problems with eating or sleeping, tantrums, or even
hyperactivity. Many pediatricians are quite skilled in the first and second line drugs for impulsive and hyperactive behaviors.

Persistent behavioral difficulties including hyperactivity that does not respond to medication, severe impulsive behavior, oppositional behavior, aggression, or self injury, is the kind of treatment that will require the attention of a specialist in behavioral psychology or a child psychiatrist who has experience with the developmentally disabled. Sometimes, individuals need referral to an epilepsy specialist first, if there is suspicion of seizures. But the long-term treatment of serious behavior or emotional problems in individuals should almost always be the responsibility of a specialist in child and adolescent psychiatry, who has the appropriate background.

**OPHTHALMOLOGY**

All children with a new diagnosis of CdLS should be referred for ophthalmic assessment. In addition to problems which may be easily recognizable such as misaligned eyes (strabismus) or shaky eyes (nystagmus), ophthalmic examination is necessary to reveal possible nearsightedness (myopia) which might be quite severe yet otherwise go undetected. If the initial examination is normal, routine ophthalmic follow-up is usually not necessary unless new problems arise. However, it may be prudent to recheck for nearsightedness every few years until puberty.

Individuals who develop recurrent red eyes, crusting on the eyelashes, itchy eyes, tearing, or eye discharge should also see an ophthalmologist. Although the symptoms may mimic a blocked tear duct (nasolacrimal duct obstruction), they are more often due to blepharitis: an idiopathic condition in which the 20 - 30 glands normally present in each eyelid have sub-optimal flow. Rather than surgical treatment for a tear duct problem, baby shampoo eyelash scrubs can often result in dramatic improvement of the blepharitis symptoms. Older children with self-injurious behavior can seriously damage their eyeballs. Any signs of self-induced eye injury should also prompt an ophthalmic referral.

**VISION**

It is not unusual for children with this syndrome to be nearsighted, have recurrent red-eye, discharge or tearing or have ptosis of the eyelids. If ptosis is severe the children may lift their chins or arch their eyebrows in order to improve their vision. Many parents opt for surgery to correct the ptosis.

Many children with CdLS may not engage in normal gaze behaviors. Gaze averting may happen for a number of reasons. It may give the child time to process visual information, it may mean the child perceives the task as too difficult, or it may mean the child is feeling uncertain or stressed. Children with CdLS may also use peripheral vision more frequently than direct gazing because they have greater difficulty choosing which of the varied stimuli should receive their attention. It also tends to be true that children who are lower functioning show greater sensory rejection and sensitivity to stimulation in their environment.

**HEARING**

People with CdLS may have very tiny structures and testing may be difficult. It is advisable to consult an audiologist and/or otolaryngologist who is familiar with CdLS or who is experienced in working with infants. Pharyngeal-esophageal tubes may be useful for middle-ear drainage as needed but a physician experienced in working with small infants is usually necessary.

If a hearing loss is suspected, headsets and hearing aids should be prescribed for infants and children. Even a mild hearing loss can result in a speech and language delay. Smaller aids are available so it is not necessary or advisable to use an adult-sized aid. If the child will not leave on the aid, an audiologist or behavioral therapist may be helpful. Appropriate audiological management should include selection and fitting of suitable amplification for all
listening environments. While the child’s personal hearing aid may be sufficient some of the time, the use of FM amplification may be necessary in other situations.

Almost all children with CdLS are diagnosed with mild to moderate and sometimes severe hearing loss, however interviews with caretakers reveal unexpected reports regarding the history of audiological results. Many caretakers report that their children were diagnosed as severely hearing impaired at birth, moderately impaired at 12 months, and mildly impaired or without impairment at age 2 years. Since it is unusual for hearing to improve rather than worsen, it seems correct audiological assessment is difficult. Individuals with CdLS may have narrow ear canals and difficult behaviors, making examinations a challenge.

Parents often report their children seem to hear much better than their test results would indicate. Considerable confusion exists regarding hearing ability for some children. Many children fitted with hearing aids will not tolerate the use of them or do so only sporadically. For these individuals, retesting is often important to insure that the aid is beneficial. There have also been reports of young children fitted with adult-sized hearing aids when child-sized aids are available and more appropriate.

ORTHOPEDICS

In the more mildly affected children curving of the fifth finger (clinodactyly), small hands, a short thumb placed closer than usual to the wrist and some limitation of elbow motions are often present, with webbing of one or more fingers (syndactyly) less common. Abnormalities of the hip occur in five to ten percent of the children with CdLS and may interfere with the ability to walk. Surgery may be used to correct this condition.

Of greater relevance to communication because of the interference in the use of sign language or other augmentative strategies for communication are the more severe upper-limb malformations. In some cases, fingers, metacarpals and the long bones of the arm are absent.

The National Agenda Moves into the New Millennium
By Kate Moss, Family Support Specialist, TSBVI, Texas Deafblind Outreach

The National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities is a set of eight priorities for the education of children and youths with visual disabilities. This document was developed by national leaders in the field of visual impairments as a result of discussions begun at the 1993 meeting of the American Printing House for the Blind (APH) in Louisville, Kentucky. The National Agenda proposed meeting these goals by the year 2000. As the century comes to a close and the new millennium is upon us, the Co-chairs, the National Goal Leaders, the State Coordinators, and the Advisory Board of that group feel a profound sense of accomplishment for the current achievements of the National Agenda.

All of the parents, professionals, and consumers who have worked toward the achievement of the National Agenda are to be applauded for their on-going efforts. Although all eight goals may not be met in all 50 states by the year 2000, the successes in many states, should be heralded. Their state plans reflect the efforts they have made to improve the quality of education for blind and visually impaired students in this country.

At the 1999 APH meeting there were over 30 attendees, the majority of whom were state coordinators. The excitement that the state coordinators have about implementing the National Agenda is still going strong. They are committed to continue until the goals are met - and this effort will not end with start of the new century.
Future National Agenda plans focus on the development of an updated *Report to the Nation*. A few of the products and projects already brought about by the efforts of this group are:

- *Annotated Bibliography for the Core Curriculum* (on TSBVI website)
- *Call to Action* (on TSBVI website)
- *Report to the Nation* (available from the American Foundation for the Blind)
- National Agenda brochure, and journal articles (available from American Foundation for the Blind)
- Early Childhood Registry Project
- *Blind and Visually Impaired Students: Educational Service Guidelines* (published by the National Association of State Directors of Special Education)

You may contact either of the co-chairs if you would like more information on these initiatives. Phil Hatlen may be reached at Texas School for the Blind and Visually Impaired, 1100 West 45th Street, Austin, Texas 78756, by phone at (512) 454-8631, or by e-mail to hatlen_p@tsb1.tsbvi.edu. Donna Stryker may be reached at 15554 Space Murals Lane, Las Cruces, New Mexico 88011, by phone at (505) 528-0403, or by e-mail to ForeverD@zianet.com.

The group will be reconvening on February 4th and 5th, 2000, in Austin, Texas, at the Texas School for the Blind and Visually Impaired. We will bring you an update on their work in future editions of *SEE/HEAR*. You may also visit the National Agenda homepage by going to <http://www.tsbvi.edu/agenda/index.htm> to keep informed of their work.

**New APH Blind and Visually Impaired Employees Recruitment Brochure**

Excerpts from the AFB Website <www.afb.org>

AFB staff have designed and produced a brochure and companion pocket folder with six inserts on recruiting blind and visually impaired employees. A complementary copy of both is available upon request, or multiple copies may be purchased at cost. The brochure is intended as a "tickler", while the information folder provides more substantive information specific to how employers and human resource personnel can make the job application and interviewing processes accessible to applicants with visual impairments, information about how blind and visually impaired workers perform their jobs, and details concerning what tax incentives and resources are available to businesses that hire people with disabilities.

These materials are ideal for rehabilitation professionals (rehabilitation counselors and teachers or job developers) to use in meetings with prospective employers and human resources department officers, or as handouts at seminars, conferences, and job fairs. Both pieces can be personalized with contact names and agency information.

For further information, please contact Karen Wolffe, AFB, (512) 707-0525; e-mail: wolffe@afb.net. To request a free copy of these materials, or for bulk-order pricing, contact AFB’s Information Center, (800) 232-5463; e-mail: afbinfo@afb.net, or visit AFB’s web site, <www.afb.org>.

AFB has many other fine publications. Here are two new items you should check out. The first is *Essential Elements in Early Intervention: Visual Impairments and Multiple Disabilities* by Deborah Chen, Ph.D. This book contains explanations of functional and clinical vision and hearing assessments, descriptions of evaluative and educational techniques, and suggestions for working with families and professionals teams. The second publication, *AccessWorld: Technology for Consumers with Visual Impairments*, is a comprehensive resource of the latest information on adaptive technology and visual impairments.
Encourage Children to Reach for the Stars
By Terrell J. Murphy, Executive Director, Texas Commission for the Blind

Preparation for a conference speech last year, I was searching for some inspiration. This particular conference theme was “Building Confidence Through Understanding,” and the Texas Commission for the Blind’s staff from across the state would be there. The conference logo was a person at the edge of the earth with outstretched arms reaching toward a bright star. The logo made me wonder how many children and adults who are blind have been encouraged to reach for the stars over the years and why some still perceive them to be beyond their reach.

Once more, I pulled out one of my favorite books, *Walking Alone and Marching Together, A History of the Organized Blind Movement in the United States, 1940-1990*, by Floyd Matson. Published by the National Federation of the Blind, this hefty book of more than a thousand pages is a collection of speeches and articles written over the years by people who are blind. Along with Matson’s narration, the book is a window into what a number of NFB members have done for themselves individually and collectively and what they have thought and felt along the way. Reading through it is one of the best ways to understand what people who are blind want understood about themselves and their organized movement.

I began to look for clues about what common thread connected each of the people in the book other than blindness. Early in the book is Jacobus tenBroek’s 1948 “A Bill of Rights for the Blind”, in which tenBroek says that idleness can confine people who are blind to the “sidelines of life, warming the bench in the game that all should play”. Reading on, the common thread is soon evident. Not one of the people in this book could be described as an idle bystander in any facet of life! Each spent a lifetime energetically reaching for his or her own star individually as well as collectively.

It’s imperative that parents and their partners (Texas Commission for the Blind and the educational and community organizations) encourage and work with kids to set goals that keep them involved and active in the full spectrum of life. A study came across my desk sometime back. It noted a survey had indicated that the kitchen is the most popular place in the house for family members to gather: all the activities of busy meal-times; kids’ homework spread across the kitchen table; mom or dad paying the bills; neighbors talking. It was the next part of the study that disturbs me. The survey found that children who are blind spend more time in their bedroom than in any other part of the house - out of the mainstream of daily life and activity. How unfortunate for these particular kids. They are missing out on some of the best day-to-day opportunities available for growing into confident adults.

As I mentioned before in other issues of *SEE/HEAR*, TCB recently completed a project called “Opportunities 2000” in which we developed a blueprint for creating the ideal children’s program. When we met with families, educators, and advocates across the state, we heard the same message: children need more opportunities in their home communities to build those foundational skills we all know are vital to being successful in life - independent living, orientation and mobility, social, career exploration, and recreation/leisure.

We’ve been working in partnership with families, educators, and community volunteers to put on special projects throughout each year that concentrate on these skills. During last fiscal year, there were 131 special projects throughout the state that gave approximately 3,400 individuals opportunities for learning and growth. Although these special projects are geared specifically for families who have children with visual impairments, many more opportunities are awaiting our children through camps, involvement with extracurricular activities, church involvement, organized sports, scouting, etc. Since we are in the process of camp registration, I encourage you to check out Ron Lucey’s article about camp found on page 33.
The opportunities we are providing are a good start, and we will be looking for ways to do more in the coming years. Continue to give us your ideas and feedback that will help us help your children reach the particular star they choose.

Placement: The Natural Outcome of the IEP
By Phil Hatlen, Superintendent
Texas School for the Blind and Visually Impaired
hatlen_p@tsb1.tsbvi.edu

IDEA identifies four processes that are to occur sequentially in serving students with disabilities. First, we must identify and refer. Next, we are to conduct an individualized assessment, in collaboration with parents/guardians. Our third responsibility is to complete an individualized educational program (IEP) for each student. And, finally, we are to determine placement, based on the assessed needs and the educational goals for each child. While there have been efforts to play with this sequence in the name of inclusive education, these IDEA principles have, for the most part, stood the test of time. Of the four processes, the last, placement, is the one that most often challenges the philosophic beliefs of both parents and professionals. In this article, I will be presenting some thoughts and beliefs about placement. I invite readers to respond, and perhaps we can begin a healthy, productive dialog.

The federal regulations written for implementation of IDEA clearly state that students with disabilities are to have available to them a continuum of placement options. Supporting this concept is the Policy Guidance on Education of Students with Visual Impairments, prepared and disseminated by the U.S. Department of Education. More recently, the National Association of State Directors of Special Education (NASDSE) has published a book entitled, Blind and Visually Impaired Students: Educational Service Guidelines, intended to provide special education administrators with directions in providing educational services for blind and visually impaired students. This publication also stresses the absolute necessity of having an array of placement options in order to address the individual needs of students.

It is clear that, if blind and visually impaired students are to receive a “Free and Appropriate Public Education” (FAPE) in the “Least Restrictive Environment” (LRE), all students must have available to them several placement options. One of these options should then be able to be “customized” in order to meet the specific needs of a particular student. To provide any less would be legally, ethically, and morally wrong.

I have been stating in recent years (having no documentation or data to back it up) that probably 90% of the blind and visually impaired students in the U.S. have only two placement options: the services of an itinerant teacher or the school for the blind. (There seem to be very few resource rooms or self-contained classrooms for blind and visually impaired children left in the country.) Expansion beyond these two options seems to depend on the creativity and flexibility of both the local school district and the school for the blind. I will expand more on this later.

THE ROLE OF A RESPONSIBLE AND CREATIVE SCHOOL FOR THE BLIND

There is no consensus among leaders of schools for the blind in the U.S. concerning the role these schools should have as we enter into a new century. As you will see, I have rather strong opinions on this subject, and I know many of my colleagues agree with me, for they have helped me mold my beliefs. I also know that there are leaders who are my colleagues who believe that, as inclusive education begins to show cracks and fails a growing number of students, blind and visually impaired children with high academic potential will be coming
back to schools for the blind in droves. I reject this latter position, primarily because inclusion, as practiced in education for the visually impaired for the past 50 years, has worked more often than not, and several generations of highly successful visually impaired adults in our communities are living and walking examples of the success of inclusive education. I also believe that parents who have the choice of keeping their children in the home, in the community, and attending a neighborhood school, will almost always opt for this over sending their children far away to a residential school.  

As much as many of my colleagues would like to live in a “black and white” professional world, I’m afraid that the only way we will succeed in providing individualized instruction to children is to live in a “gray world”. I find myself very comfortable in a gray world, but I know, and Myers/Briggs results verify, that there are many of us for whom gray is terribly uncomfortable. Thus, my description of what you should expect from a school for the blind is continually being adjusted, is continually shifting, and must be allowed the flexibility to answer to the needs of today and tomorrow.  

I will address this to teachers, parents, and administrators in Texas. If those of you from other states and countries find value in this, I will be pleased. But my purpose is best served if I specify as my audience my fellow Texans.  

The Texas School for the Blind and Visually Impaired (TSBVI) is committed to providing services, as needed, to all blind and visually impaired students in the state. For the more than 6,500 students in Texas that are identified as visually impaired, TSBVI must provide a wide variety of services. Colleagues in education service centers and in local school districts and parents have guided us in determining the services we need to provide.  

TSBVI believes that blind and visually impaired students should be educated, to the greatest extent possible, in their local school districts. We believe that quality services at the local level require tremendous commitment from school districts, and if that commitment doesn’t exist, services provided might be less than desirable.  

SERVICES OFFERED BY THE TEXAS SCHOOL FOR THE BLIND AND VISUALLY IMPAIRED  
On-Campus Services  
TSBVI must be prepared to meet the needs of the following students with quality education and residential services:  

1. Blind or visually impaired students with additional disabilities. TSBVI provides a variety of educational settings for these students, always in small classes with excellent adult/student ratios. Often these students are in need of highly specialized approaches to communication, mobility, social interaction, and understanding and reacting appropriately to their environments. Over the past several decades, TSBVI has become very adept and creative in serving this population, always taking into consideration the environment in which a child might live as an adult. TSBVI provides extensive community-based instruction in natural environments for these students.  

2. Despite a recent intensive and successful effort to increase the number of highly specialized teachers for blind and visually impaired students in Texas, there are numerous areas of this state where providing support to the classroom teacher with a qualified teacher of the visually impaired remains a serious problem. Students residing in these geographic areas might need to come to TSBVI for a regular education program. Thus, for these students, TSBVI has a responsibility to continue to offer an educational program that is similar to what is provided in a local school.
3. Sudden vision loss may require a change in learning media for a student. It may impact the child in other profound ways, also. Some students who move from reading normal-sized print to large print, or from print to braille, benefit greatly from a “time-out year”, an opportunity to learn new basic skills for accessing learning. TSBVI must be ready to offer an intensive year of instruction in reading and writing, auditory learning, orientation and mobility, independent living skills, social interaction skills, etc. These students may benefit from a less strenuous academic learning time, and TSBVI can adjust its curriculum to accommodate this need.

4. There are students who succeed academically in all areas with the exception of one or two. For example, it is not unusual for a blind or visually impaired student to excel in language arts, in history, etc., and have serious learning issues in mathematics and science. In other cases, the student might benefit greatly from intensive instruction offered at TSBVI in physical education, in orientation and mobility, in fine arts, including music, etc. TSBVI is capable and eager to provide specific instructional programs to students for one or more semesters.

5. As students approach high school graduation, there may be a need to provide intensive vocational education instruction for some. TSBVI must (and does) have the flexibility to admit students in their late teens for an educational program that stresses work readiness.

6. There are students who need the experience of attending TSBVI for less definable reasons. Sometimes students can experience real (not artificial) success at TSBVI beyond what they can achieve in their local schools. Many students who are referred to TSBVI, are described by their parents and their local school as having low self-esteem. Success, in athletics, in music, in drama, and in social interaction, often happens first on the campus of TSBVI.

7. Recognition of the “Expanded Core Curriculum” for blind and visually impaired students has challenged both schools for the blind and local schools as they explore ways in which these needs can be met concurrently with the regular core curriculum. As local schools face the real possibility that overworked itinerant teachers have little, if any, time to address the expanded core curriculum, TSBVI must step forward and offer school districts options for meeting these needs. This is not to suggest that local schools should consider themselves “off the hook” for the expanded core curriculum. But they and TSBVI must work together to assure that all Texas students receive appropriate instruction in all areas of this curriculum. In some instances, one or two years at TSBVI will be what is necessary for meeting these needs, and we are ready to, and capable of, providing this instruction.

8. TSBVI is expanding its Special Programs that will be offered on campus. For many years, an extensive summer program has been a part of the TSBVI services, and in 1999 - 2000 we will be offering similar short-term courses during the school year. Summers at TSBVI have offered blind and visually impaired students an opportunity to meet and become friends with other visually impaired age-mates. They experience an environment where perhaps the pressure of going to school with sighted peers is lessened, and visual impairment, as one characteristic of the child, is celebrated. Certainly skills are learned during summer programs, particularly in the area of vocational education. But these are, for the most part, enrichment opportunities for students, and no attempt at meeting IEP goals is made.

Perhaps a stronger emphasis in the expanded core curriculum will mean a partial change in the TSBVI summer program. Indeed, if local districts call on us to meet curricular needs in areas such as social skills, living skills, technology, etc., we will respond to such a request. We have both the facilities and an expert staff to provide intensive instruction in the expanded core curriculum. TSBVI expects that short-term programs during the school year will also address the expanded core curriculum.
As is evident, TSBVI is capable and ready to meet the individual needs of blind and visually impaired students in Texas by providing a variety of on-campus instructional opportunities. We are ready to address specific needs for an individual student, as identified by parents and the local school district. Our promise to local schools and parents/guardians is that we will work intently on the needs that caused the referral of the student, so that the student can return home and to the neighborhood school as soon as possible.

**OFF-CAMPUS SERVICES**

TSBVI is responsible in some manner for the education of all blind and visually impaired students in Texas. This is a legislative mandate, and it is a responsibility we assume when we consider ourselves as the “hub” of education for blind and visually impaired students in the state. As I have described, we meet that mandate by providing a wide array of on-campus educational opportunities for Texas students. But what about the thousands of students who never set foot on our campus?

Of all the services provided by TSBVI, our Outreach Department is probably best known statewide. We have been fortunate in assembling a gifted, highly trained and experienced professional staff to serve in our Outreach Department. What began as a technical assistance program for teachers, administrators, and parents, has grown to include many other components that impact on the education of all children in the state. Among these are:

1. Offering statewide staff development for professionals serving blind and visually impaired students.
2. Providing a process by which local districts can evaluate the quality of their programs for blind and visually impaired students (the Quality Programs for Visually Impaired or QPVI process).
3. Administering statewide registration of all blind and visually impaired students.
5. Offering conferences and workshops for both professionals and parents.
6. Providing consultation services for infant and preschool blind and visually impaired children and their families, including those who are deafblind.
7. Providing a variety of services for deafblind students, including technical assistance to families and schools, parent counseling, assistance in transition planning, and training of staff to work with students in local schools.

Two additional off-campus services that must be highlighted are:

1. Curriculum development. TSBVI develops curriculum guides for its on-campus students, then publishes them to make them available throughout Texas and the world. This is a responsibility that TSBVI accepts as a part of being a center for learning for blind and visually impaired students.
2. The TSBVI website has also become known worldwide, and is acclaimed as having timely and pertinent information for parents and professionals.

Off-campus services do not exactly fit the term “placement” as it applies to schools for the blind. However, I would contend that the education of most, if not all, blind and visually impaired students in Texas is a shared responsibility between the local district and TSBVI. Thus, in a way, all students have a “joint placement” if we consider the term to mean services, and not a place.

**QUALITIES NECESSARY IN LOCAL SCHOOL SERVICES**

There is no more treacherous ground on which a superintendent of a school for the blind can travel than the
topic of educational placement for blind and visually impaired students. If we celebrate our accomplishments and share our expertise, some may consider us recruiting. If we build a wall around us and shut ourselves off from the rest of education and the community, we will soon die. So, what should we do? I have taken the position that blind and visually impaired students in Texas should be provided appropriate educational services in their local schools, in their home communities. They should be able to live at home with their families, and receive an education that is as good as that provided to their sighted age-mates. In the few cases where this might not be possible, the school for the blind is ready and eager to serve students. If there are areas of learning that might be better achieved at the school for the blind, we are prepared to provide intensive, specific short-term programs. Thus, the Texas School for the Blind and Visually Impaired (TSBVI) serves in a collaborative and cooperative manner with local school districts, meeting needs as mutually determined by the local school, the parents, and TSBVI.

I have become rather glib in describing this highly desirable relationship with local districts, assuring parents, teachers, and administrators that we stand ready to help when called upon. However, when I shed my role as Superintendent of TSBVI, and consider what I really am, an educator for blind and visually impaired students, I am challenged to describe what I consider to be an appropriate education for blind and visually impaired students in their local schools. I am vain enough to believe that I can be an unbiased evaluator of educational placement, one who can keep the playing field level for all placement options. If I can keep the needs of a child as the most critical ingredient in making a placement decision, then I am able to see beyond the assets and liabilities of specific placements.

So, here we go on dangerous ground. I’m going to describe to you the conditions that must exist at the local school district level if blind and visually impaired students are to receive an appropriate education. Education of the highest quality can be available in local schools under the following conditions:

1. The local school board, the school administration, the school staff, and the parents solidly support blind and visually impaired students in their schools. This support must be more than philosophic; it must be financial. Blind and visually impaired children are among the most expensive students to include in general education. If they do not receive what they require for specialized instructional support, for related services, for adapted instructional materials, and for very specialized equipment, then the local placement will be less desirable.

2. Placement decisions made by the local IEP committee must be based on the individual needs of each student, as determined by a comprehensive assessment, not by philosophic beliefs or current educational trends.

3. Every blind and visually impaired student must have available to her/him a highly-trained educational specialist. This teacher must serve multiple roles. She/he must be a materials provider, a consultant, a counselor, an advocate, and a teacher. This latter role is crucial. If the specialist teacher for the visually impaired is relegated to the role of academic tutor, or a case manager, then the child will not be well-served, and the placement may not be appropriate. The specialist must have time to teach, or the student’s learning is at risk.

4. All necessary related services personnel must be available to the student, based on needs identified in the comprehensive assessment. Especially important is the availability of appropriate orientation and mobility services. Although orientation and mobility instruction is considered a related service in IDEA, it is recognized as a necessary area of instruction for blind and visually impaired students. If a student is determined to need a speech and language specialist, or a physical therapist, or any other approved related service, this needs to be provided. Under the best circumstances, the related services personnel will be experienced in providing services to blind and visually impaired students.
4. The local school district, including its Board and administration, must acknowledge the absolute necessity of providing the blind or visually impaired student the expanded core curriculum. This must be a district-wide commitment, because in many school districts, implementation of the expanded core curriculum will require creative thinking and adjustments to the manner in which the time of the specialist teacher of the visually impaired is used. To ignore the expanded core curriculum is not acceptable, and will result in an inappropriate placement.

I consider these my non-negotiables in supporting local school district placements for blind and visually impaired students. Perhaps some of you will want to take issue with these. Perhaps others would like to add additional points. I welcome dialog on this topic.

Texas Interveners Attend van Dijk Training
By Kate Moss, Family Support Specialist, TSBVI, Texas Deafblind Outreach

An intervener is a paraprofessional with specialized skills and training in the field of deafblindness. The intervener is designated to provide direct support to a student with deafblindness for all or part of the school day. The intervener supports the existing service delivery model in implementing the student’s IEP. The decision to use an intervener is based on the level of support a student currently needs to appropriately participate in his/her instructional environment. The question of using an intervener should only be addressed after the student is assessed, the IEP is developed, and the available service delivery options are reviewed.

The use of interveners with students with deafblindness has occurred for only seven years in Texas. The effectiveness of the model has been validated, however, through wide-spread use for many years in Canada, and more recently in Utah and several other states. Some states are using this support model in both home and school settings, but each state has taken a slightly different approach to funding these positions and determining how a child will access this type of support.

The Texas Deafblind Outreach Project has made this a primary focus of their grant activities for the next four years. It is hoped that through our technical assistance efforts, schools and families will have support in determining when an intervener is appropriate for a child and how to go about hiring and training the individual for this role. Currently an effort is being made in Texas to develop a set of competencies for interveners, to better define the scope of their work, and to provide school districts with guidelines for using interveners with students who are deafblind. An annual intervener meeting and other training opportunities for interveners and the staff supporting interveners is planned to help school districts use this service model in an effective way.

On November 6th - 8th, twenty interveners from around Texas traveled to Austin for the second Annual Intervener Meeting which was held in conjunction with a special two-day workshop presented by Dr. Jan van Dijk. The interveners met on Sunday afternoon to share information about their work with deafblind children and to discuss issues related to performing their jobs. Much of the discussion on Sunday focused on some of the logistical issues that must be addressed when school districts consider employing an intervener. On Monday and Tuesday, the interveners had the opportunity to attend Dr. van Dijk’s workshop. Each intervener was joined by one of their team members at the van Dijk workshop.

A document has been prepared by the Texas Deafblind Outreach team titled, “Interveners for Students with Deafblindness in Texas: A Model of Individual Support to Provide Appropriate Access to Education for Students who are Deafblind.” This document was created by families, educators, and administrators in a series of planning meetings held in 1993-94 and refined in 1999, based on the past several years of piloting this service delivery model. This document will help families and school districts make decisions about using an intervener.
in the school setting with a student who is deafblind. If you or your school district would like a copy of this document or more information on the use of interveners, please contact Cyral Miller with the Texas Deafblind Outreach at (512) 206-9242.

The Paraprofessional Working with Students with Visual Impairments
By Jim Durkel, Statewide Staff Development Coordinator
with help from Cyral Miller, Outreach Director
TSBVI, Outreach Program

Last spring I attended a national conference on and for paraprofessionals working in public schools. I have thought about that meeting and would like to share some of my thinking with you.

WHAT IS A PARAPROFESSIONAL?
Paraprofessionals are people who have not completed a professional education degree (are not teachers) but have jobs that support instruction for students. These could include people called teacher aides or paraeducators who work in the classroom. Braillists, who don’t work with students directly but spend their day preparing materials for one or more students, could also be included in this group. In some school districts, one paraprofessional may serve both roles. In some school districts, one paraprofessional may provide support to a student with visual impairments part time and work with other students in the classroom part time.

WHAT DOES A PARAPROFESSIONAL DO?
The paraprofessional’s role is to support the teacher, either the classroom teacher and/or the teacher for students with visual impairments, and/or others working with the student. The support is centered on specific IEP goals and objectives for the student. This support can include modifying materials, assisting with reading overheads or writing on the blackboard, giving one-on-one assistance in specific tasks, helping control behavior problems, providing opportunities for practice to reinforce previously learned skills, or collecting data related to IEP objectives. A paraprofessional should always be thinking about how a student can be independent in a task and give just enough support so the student is successful, but not so much that the student does not have to make much effort.

Sometimes paraprofessionals are asked to do jobs for which they do not have certification or legal authority. Paraprofessionals should not make decisions about what material should or should not be taught. Paraprofessionals should not teach braille. They can reinforce braille skills, but only a teacher for students with visual impairments can teach braille. Similarly, the paraprofessional does not teach new orientation and mobility skills. They should reinforce the skills the certified orientation and mobility specialist has taught. The paraprofessional should not decide what technology a student might need, how much homework a student should or should not do, nor design a behavior plan for any student. That function is reserved for the ARD committee.

A paraprofessional has specific roles to help support instruction. In meeting that goal, a paraprofessional should not have to take emotional or physical abuse from a student. Paraprofessionals help in sure continuity of instruction, but should not serve as the go between for classroom teachers and the teacher for students with visual impairments or the teacher for students with visual impairments and the family. The paraprofessional should learn to come in and fade out as needed, rather than hover over and smother students.

HOW CAN WE HELP THE PARAPROFESSIONAL DO HIS OR HER JOB BETTER?
That can be summarized in two words - training and supervision. Paraprofessionals need training just as
any one doing any job does. We cannot hire some one with no background (having gone to public school themselves does not count as training) and expect them to work with our students.

All paraprofessionals need training in how to deal with inappropriate behavior, how to prompt, how to fade supports and how to reinforce desired responses. They should know their role and job duties and have a clearly defined “line of command”.

They should know who will evaluate their performance based on what criteria. They should know where to go for support and with grievances. All paraprofessionals need to know about universal health precautions. All need to know how to recognize and report child abuse or neglect.

Paraprofessionals working with students with visual impairments need additional training. They need to know about a particular student’s visual impairment and how that impairment will affect learning. They need to know how to modify materials for that student. They may need to know the braille code. They may need to know how to use a computer to assist in producing braille. They may need to know about the technology a child is using so they can help troubleshoot. They may need to know how a child should use a particular low vision device. They need to know basic orientation and mobility techniques, such as sighted guide. They may need to know how to help a student organize her space. They need to know how to deal with a student’s emotional responses to being different. They need to know how to reinforce social skills and daily living skills.

Who will provide this training? Most education service centers now offer training to all paraprofessionals in the basic areas. There are currently no standards for training, as we do not certify paraprofessionals in education in Texas. However, that may change in the near future. The current IDEA, the Federal law dealing with special education, states that training needs for any member of the educational team can be addressed during an IEP meeting.

The best place for a paraprofessional working with a student with visual impairments to get VI-specific training is from the vision professionals. This ties in with supervision. The paraprofessional is there to help a child meet IEP objectives. Ultimately the professional responsible for those objectives is the classroom teacher, teacher for students with visual impairments and/or certified orientation and mobility specialist. It is important, then, that these professionals provide support to the paraprofessional. This support would include clear training on how to work with a student with a particular type of visual impairment. It would also include enough training so that the paraprofessional could provide support not only in the regular classroom activities but also in the extended core curriculum areas; recreation and leisure, compensatory skill use, daily living skills, social skills, etc.

This kind of training requires regular, ongoing contact and support. The teacher for students with visual impairments and certified orientation and mobility specialist, have a responsibility to observe paraprofessionals on a regular basis to insure their work is appropriate. Again, it is these professionals who are responsible, along with the classroom teacher, for a student’s success (or failure) on IEP goals and objectives. It would be embarrassing to show up at an IEP meeting and say the student did not meet these objectives because the paraprofessional did not know what to do or was doing something in a wrong manner.

The ongoing support also should include a discussion about the paraprofessional’s role with other students in the classroom. The teacher for students with visual impairments and classroom teacher must sit down (probably with an administrator) and agree on the paraprofessional’s roles. It is important to recognize that most students with visual impairments do not need full time paraprofessionals. Instead, a given student’s IEP must be considered. Does the student need support during a particular subject? Is the student taking a science course with much lecture and where many graphics are used? Or is it a hands-on science course and a good
peer lab partner would be better than adult support? Is this a student who will need tactile symbols? These symbols require making, repair, and storage. Is the teacher for students with visual impairments going to need help to do this? Does the student need support to use an adaptive mobility device? How is braille going to be produced so that the student gets it in a timely manner?

WHAT IS THE ROLE OF PARENTS?

Parents can play an important role in the support of paraprofessionals. At the IEP meeting, parents may want to raise the issue that the teacher for students with visual impairments and certified orientation and mobility specialist will need time to train and observe the paraprofessional and that the paraprofessional may need release time to attend training.

Parents, please do not use the paraprofessional as a “shoulder to cry on” and complain to them about the teacher for students with visual impairments or classroom teacher. If you have issues with those professionals, please address them directly. If you have concerns about the work of a paraprofessional, ask for a staff meeting to address those concerns.

TO PARAPROFESSIONALS

Thank you for the work you do. You help in so many ways. You have the right to get training so that you can be effective in your job. You have the right to ask for the teacher for students with visual impairments and certified orientation and mobility specialist to regularly observe your work and give you feedback and support. You may need to take an active role in asking for that training and support. There are materials designed for you to help you do your job better. One good resource is *A Paraprofessional’s Handbook for Working with Students Who are Visually Impaired*. This book is available from Texas School for the Blind and Visually Impaired at a cost of $25. A second and very excellent resource is *Classroom Collaboration* by Laurel Hudson, and is available from the Perkins School for the Blind. You can call (617) 972-7367 for ordering information.

Y2K – Yes to Kamps

By Ron Lucey, Consumer Resources Coordinator, Texas Commission for the Blind

Each year I enjoy sharing information about summer camps with SEE/HEAR readers. I hope to inspire you to look now for the sleeping bag and mosquito netting. Even before the bluebonnets blossom, camp sessions may already be filled. Three exceptional residential summer camps, each accredited by the American Camping Association for safety and quality, are featured here. A more complete and updated listing of Texas summer camps is on the TSBVI web site <www.tsbvi.edu>. Your local TCB children’s caseworker, transition counselor, or VI teacher may also have more information on local and regional camps.

CAMP CAMP (CHILDREN’S ASSOCIATION FOR MAXIMUM POTENTIAL)

Camp CAMP provides integrated camping for children with disabilities and their siblings. It has a reputation for accepting children who may have been rejected by other camps due to the severity of their disability. Camp CAMP’s director, Sam Van Neste, proudly boasts, “We have a zero rejection policy.” An onsite-staffed infirmary and a one-to-one camper to staff ratio affords it the ability to accept any child with a disability.

Located in Center Point, Camp CAMP serves campers ages 3 - 21 and offers traditional camping activities, including canoeing, swimming, arts and crafts, and horseback riding. With all it has to offer, your child will likely achieve greater self-confidence from the exploration of these new experiences. Parents will also benefit from a week of much needed respite while children are participating.
Six sessions are offered this summer, and each focuses on a specific developmental disability. Respite and weekend sessions are also available throughout the year. All camp sessions cost $475 with a sliding fee as low as $100. Summer camp applications will be available after January 1. The deadline for receiving applications is May 1, 2000. Contact Camp CAMP to request an application and a camp schedule.

Camp CAMP, PO Box 27086, San Antonio, TX 78227
Phone: (210) 292-3566; Fax: (210) 292-3577
Website: <www.serve.com/campcamp>

CAMP SUMMIT

Camp Summit is located north of the Dallas-Fort Worth Metroplex in Argyle on 117 beautifully wooded acres. The camp provides residential barrier-free camping for persons with special needs. Camp Director Lisa Braziel says, “We focus on abilities rather than disabilities. The camp staff encourage the skills that campers already have and reinforce what the family is working on.” Camp Summit serves children from the age of 6, youth and adults who are physically challenged, developmentally delayed, dual sensory impaired (deafblind) and multidisabled. No limit is placed on the extent of disabilities as long as the camp can meet medical needs. Two nurses handle medications and a doctor is on-call. The camp ratio is a counselor for every two campers.

Camp Summit offers swimming, horseback riding, wilderness and nature study, arts and crafts, fishing, and a ropes course that will challenge campers and build their self-confidence. All activities are adapted to the individual camper’s ability. Camp Summit places an emphasis on social skills. All activities occur as a group. Bonfires and evening dances allow campers to practice their social skills while having fun.

Summer programming is divided into ten one-week age and disability appropriate camp sessions. The camp also offers a one-week deafblind camp for individuals ages 6 - 50. Camp availability is offered on a first-come, first-served basis. Respite services are also available on weekends during the fall.

The cost of Camp Summit is $500 per week. A sliding fee is available to residents who live in the Dallas United Way service area. Applications for Camp Summit will be available in February. Applications must be completed and received by Camp Summit ten days before each camp session. The camp staff encourages parents to contact Camp Summit with questions and attend the open house during the first Sunday in May.

Camp Summit, Inc., 2915 LBJ Freeway, Suite 185, Dallas, TX 75234
Phone: (972) 484-8900 or (972) 620-1945
E-mail: campsummit@campsummittx.org
Website: <www.campsummittx.org>

TEXAS LIONS CAMP

The Texas Lions Camp is located in Kerrville on 500-plus acres in the Hill Country. Texas Lions Camp provides, without charge, a camp for the physically disabled, hearing/vision impaired, and diabetic children. Last year the Lions Camp celebrated its 50th year of providing residential camping and respite services to Texas children with disabilities and their families. This year, the Texas Lions Clubs have set a goal to sponsor 2,000 campers. The camp is undergoing some renovations to improve access such as the addition of an accessible Olympic swimming pool, expanded dining hall, and a shaded picnic area with three new pavilions.

The Lions Camp serves children ages 6 - 17 with physical disabilities, and children ages 9 - 16 with type 1 diabetes. Although the Lions Camp has onsite medical staff, they limit the number of campers who have specific medical conditions and disabilities. Many parents feel the main benefit their child received from Lions Camp is an improved sense of confidence. "Children are building self-esteem, and building relationships and
Highlights of the November AVIT Meeting
By Kate Moss, Family Support Specialist, TSBVI, Texas Deafblind Outreach

AVIT is an interorganizational coalition committed to speak on behalf of Texas’ children and adults with visual impairments. AVIT met on November 18 at TSBVI. Here are some highlights of the November meeting:

AVIT acknowledged the new Health and Human Services Commission (HHSC) umbrella should not be seen as a defeat for Texas Commission for the Blind (TCB) since most of the program functions of TCB will continue as they have in the past. The HHSC changes were done to increase interagency administrative efficiency and to save money. Additionally members were pleased to hear about the approval of additional funds which will be used to hire three additional TCB children’s caseworkers in Dallas, Waco, and Austin.

A report was made about the Literacy Conference held in San Francisco in November. One of the major debates at this conference was about teaching grade 1 braille (uncontracted), grade 1 1/2 (some contractions), or grade 2 braille (contracted) to the child just learning to read braille. AVIT will encourage blindness organizations to pursue research on braille literacy to address this issue.

AVIT wants to encourage more parental involvement in guiding the state agenda for individuals with visual impairment. This is especially important when the state Legislature is in session and parents are needed to testify about specific pieces of legislation that may affect their children. A letter will be drafted and sent to parents to inform them about AVIT and parent organizations in Texas and encourage their involvement in advocating for services for individuals with visual impairment.

AVIT also wants to remind consumers, parents and professionals concerned with issues related to visual impairments, about the toll-free number they can call to hear what the latest issues are. That number is (800) 394-0666. It is important for interested individuals to stay abreast of changes that may effect them and/or their family by calling this number periodically.

The next AVIT meetings will be on March 23, 2000 at TCB in Austin and on June 22, 2000 at TSBVI in Austin. If you would like to become a member of AVIT, whether you represent an organization (organizational dues $50) or just yourself (individual dues $10), please contact Mary Ann Siller, AVIT Treasurer at (214) 352-7222 or write to her at American Foundation for the Blind, 260 Treadway Plaza, Dallas, TX 75235.
14th Annual Josephine L. Taylor Leadership Institute (JLTLI)  
March 3 - 5, 2000 in Dallas, Texas

Meetings are about people sharing ideas and information, and setting common goals for the future. There is no better place than the JLTLI 2000 to develop an understanding of the complex nature of the vast issues confronting the field of blindness and visual impairments; respond and exchange opinions; refine a community action plan in tune with our constituency; and, at the same time, forge new alliances with colleagues from your community and throughout the United States.

American Foundation for the Blind (AFB) invites you to join them in Dallas, Texas, from March 3 - 5, 2000. AFB will bring the leading policy conference (JLTLI) in the field of blindness to Dallas, the regional home of AFB Southwest.

This year’s theme is: “Achieving an Accessible World: Partnerships, Roadblocks and Opportunities.”

JLTLI is for parents of children with visual impairments, consumers, and professionals working with children and adults. JLTLI will feature renowned speakers from the private and public sectors outside the field of blindness – the world in which we must work to achieve full access by people who are blind or visually impaired – and experts from within the blindness field to spell out the implications for our programs.

Early-Bird Registration: $235 by February 4, 2000  
Pre-registration: $285 by February 24, 2000  
At-the-door Registration: $325  
Where: Dallas Marriott Quorum  
14901 Dallas Parkway, Dallas, TX  
Room Rates: single at $102 and double at $112

For more information, please call:  
Mary Ann Siller, National Co-chair for AFB’s Education Program,  
at (214) 252-7222 or siller@afb.net

Parents Building Partnerships  
March 5, 2000 in Dallas, Texas

Following JLTLI, NAPVI will be sponsoring a free workshop “Parents Building Partnerships” on March 5 from 2:00 - 5:00 p.m. at the Dallas Marriott Quorum, 14901 Dallas Parkway, Dallas, TX. This workshop is designed for parents to assist them in understanding the changes made in the Individuals with Disabilities Education Act Amendments of 1997. This will help parents to make informed choices for their child’s educational program. Even if you are unable to attend the JLTLI 2000, please join other parents for this afternoon training.

For more information, please call:  
Susan LaVenture, Executive Director of NAPVI  
(800) 562-6265.
Announcing the
Third Annual Usher Family Weekend
April 29 - 30, 2000
Austin, Texas

Dates have been set for the Third Annual Usher Syndrome Family Weekend. This retreat, for families of children and teens with Usher Syndrome, will be held at the Four Points Hotel in Austin. Everyone had a great experience last summer, and made plans to meet again. If you haven’t come before, it is a wonderful opportunity to have fun and learn while you meet and visit with a lot of cool kids and families. The entire family is welcome, so put it on your calendar!

For more information, please contact:

David Wiley, Transition Specialist
Texas Deafblind Outreach, TSBVI
(512) 206-9219
wiley_d@tsb1.tsbvi.edu

Or, to share your ideas about the weekend drop into:

the Family Discussion Room on the TSBVI Website
at <www.tsbvi.edu>

Through Your Child’s Eyes

Have you ever wondered how your child “sees” the world? Have you ever considered what a world with little or no sight might be like? If these questions seem important to you, then Through Your Child’s Eyes was designed with you in mind. At this workshop you will have the opportunity to:

- meet other parents of children with visual impairments and deafblindness
- learn how the eye works and how your child’s visual impairment impacts his vision
- participate in activities that simulate visual impairments
- learn about the resources available to you and your child
- learn about advocating for quality programming for your child
- meet adults who have visual impairments

Target audience: Parents of young or recently diagnosed children with visual impairments, including multiple impairments. This workshop has been scheduled in the following locations:

**Waco: February 25 - 27, 2000**
Contact: Tina Herzberg at ESC 12
(254) 666-0707
or
Mollie O’Leary at TCB
(254) 753-1552

**Midland: March 24 - 26, 2000**
Contact: Tamee Argo at TCB
(915) 368-0881

**Ft. Worth: April 28 - 30, 2000**
Contact: Judy Hamilton at TCB
(817) 926-4646
INSITE:
A Home-Based Model for Infants, Toddlers, & Preschoolers Who Are Sensory Impaired with Other Disabilities

Austin, TX
May 15 - 20, 2000

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 it to your area, please contact:

Gigi Newton
Texas Deafblind Outreach, TSBVI
1100 West 45th
Austin, TX 79756
(512) 206-9272
newton_g@tsb1.tsbvi.edu

Be a Mentor
Mentors are still needed for all the new VI teachers and O&M specialists trained through the VIP Program in Texas. The next mentor training is:

April 28 - 29, 2000
Houston, TX
Region 4 Education Service Center

All expenses including travel, meals and lodging are paid for by the mentor program. If you are interested in helping a new VI professional “learn the ropes” about itinerant teaching, please contact:

Ruth Ann Marsh, Mentor Coordinator
Texas School for the Blind and Visually Impaired
Phone: (512) 206-9203
E-mail: marsh_ra@tsb1.tsbvi.edu

TAER Conference:
“And Literacy for All”

April 13 - 15, 2000
Airport Hilton Hotel
San Antonio, TX

For further information, contact Debra Sewell at TSBVI
Phone: (512) 206-9301
E-mail: sewell_d@tsb1.tsbvi.edu

Interagency Council on Early Childhood Intervention Conference 2000
Partnership: Strengthening Connections, Linking Families, Communities and Resources

Renaissance Austin Hotel,
Austin, TX
May 1 - 3, 2000

For more information contact:
Suzy Armstrong
(512) 424-6777

Make your summer plans around this event!

Texas Focus 2000

a conference for families and professionals about educating children with visual impairments and deafblindness

Reserve the dates: June 14th - 16th
Location: El Paso, TX

For more information please contact Jim Durkel at (512) 206-9270 or durkel_j@tsb1.tsbvi.edu.

International Parent to Parent Conference
May 5 - 7, 2000 in Reno, NV

This is one of the largest conferences of parents and families in the world. Parents/families and professionals from around the world come together to share and learn from each other about how best to support families and develop best practices for people with disabilities.

Contact: Cheryl Dinnell
Phone: (702) 784-4921, ext. 2352
E-mail: cdinnell@scs.unr.edu
Visions for the Future: Finding Your Way From High School to Your Future
May 5 - 6, 2000
Baptist Retreat, Lone Star, TX
Presenter: Karen Wolffe, Ph.D.
Sponsored by Region 8 ESC and Texas Commission for the Blind
This special workshop is for 12 - 18 year-olds interested in finding a direction from high school, their parents, and VI teachers.
Registration Fee: none
Contact: Donna Clopton at (903) 572-8551

AER International Conference
AERodynamics: Soaring to New Heights
July 14 - 18, 2000
Adams Mark Hotel Denver, CO
For more information please contact:
Denise Rozell, Executive Director
Phone: (703) 823-9690
E-mail: drozell@aerbvi.org

REGIONAL WORKSHOPS/CONFERENCES
March 10, 2000
Career Day
Region 8 Education Service Center - Mt. Pleasant
Presenter: Panel of employed people who are visually impaired
Audience: 7th - 12th graders, teachers, parents, TCB
Registration Fee: none
Contact: Donna Clopton at (903) 572-8551

March 30, 2000
(Teleconference) Uses of Low Vision Devices
Region 8 Education Service Center - Mt. Pleasant
Presenter: College of Optometry, University of Pennsylvania
Audience: VI teachers and parents
Contact: Donna Clopton at (903) 572-8551

NATIONAL/INTERNATIONAL EVENTS
March 14 - 18, 2000
Capitalizing on Leadership in Rural Special Education: Making a Difference for Children and Families
Alexandria, VA
Sponsor: American Council on Rural Special Education (ACRES)
Contact: ACRES Headquarters, 2323 Anderson Ave., Suite 226, Manhattan, KS 66502-2912
Phone: (785) 532-2737
E-mail: acres@ksu.edu
Website: <www.ksu.edu/acres>

April 5 - 8, 2000
CEC Annual Convention
Vancouver, BC
Division on Visual Impairments
The Council for Exceptional Children
Phone (toll free): (888) 232-7733

July 29 - August 4, 2000
American Association of the Deaf-Blind National Convention
Columbus, OH
For information visit the AADB website at <http://www.tr.wosc.osshe.edu/dblink/aadb.htm>.

Missing: Perkins Braillers
Over 900 Perkins Braillers are scattered around Texas. Many are not producing braille, but may be broken, gathering dust in closets, or used as door-stops. There are children in Texas who need these Braillers. If you have one, please return it to:

Nick Necaise, TIMCVI
TSBVI
1100 W. 45th St.
Austin, TX 78756

or call Nick at (512) 206-9335;
e-mail: necaise_n@tsb1.tsbvi.edu
SEE/HEAR

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Deadlines for articles are:
December 1st for the Winter edition
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June 1st for the Summer edition
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The audio version of SEE/HEAR is provided by Recording for the Blind and Dyslexic, Austin, TX.

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

If you no longer wish to receive this newsletter, please call (512) 206-9314.

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