

# SEE/HEAR

A QUARTERLY NEWSLETTER ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS  
A collaborative effort of the Texas School for the Blind and Visually Impaired and  
Department of Assistive and Rehabilitative Services, Division for Blind Services

Summer 2005

Volume 10, No. 3

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## Things to Keep in Mind: A Parent's Perspective

By Christi Ambramsky, Parent, Rockwall, TX, and  
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*Abstract: The authors share a selection of things to keep in mind regarding the life and family of a child with special needs.*

*Keywords: personal experiences, family, parenting, special needs, professional service providers*

*Editor's Note: Christi came to the ESC 10 Baby's Luncheon with an amazing variety of "active learning" items that she had created for her son, Eli. Eli is two years old now and his main diagnosis is agenesis of the corpus callosum. He also has cortical vision impairment, unilateral moderate hearing impairment, delayed development, and a number of other medical issues. Christi has developed a sense of what works with children with sensory loss and is eager to share it with both parents and teachers. She can be contacted by email at <casam3@att.net>.*

Recently, I returned to college after working for many years as a computer programmer, my chosen field as a young college student. Although still enamored with computers and technology, I recognize now that people are often guided by lifetime events and circumstances that change career direction. After our fourth son was born with special needs, computer programming did not fulfill me as it had at one time. After dealing with a great deal of fear and reluctance, I quit my job in order to go back to school. In a few semesters, I will graduate with a degree in special education, enabling me to help children like my own and allowing me to teach in a field desperate for qualified educators.

After some persuasion, I recently volunteered to speak to one of the special education classes in which I was enrolled. The course, "Introduction to Special Education", is designed as comprehensive review of pertinent information regarding all aspects of special need learners including terminology, classification, characteristics, litigation, inclusion and parenting. When we began the chapter regarding families, I volunteered to speak to my class about parenting a special child. Although I often talked to many individuals casually about my son's unique needs, I had never formally addressed a group about the subject.

I found the talk to be very therapeutic and suspect that my classmates gained more from my personal experiences than the textbook chapter could deliver. As a result of the preparation and introspection required for this public dialog, it occurred to me that there are a number of things I wish every person that we interact with knew. So, to doctors, nurses, therapists, friends, educators, acquaintances and family: I offer this list of "Things to Know!" Without the personal experience of parenting an exceptional child, these items were hard lessons, but soon learned along life's journey with my beautiful son.

### **1. There is no reason for you to be sorry.**

It seems to me that the first number reaction people offer when they find out that we have a child with special needs is "I am sorry"! People are being kind when relaying sorrow that something so difficult has happened to us but, in fact, it is not necessary. We are not sorry! Our child is a gift and we embrace him – all of him and all of the things that come with the territory. His disabilities, his 12 doctors, his 5 therapists, all of the love and joy, all of the wonderful lessons that he had taught and the empathy for differences that he will teach our other children. There is no reason for you to be sorry, we aren't.

## 2. We might need a little extra support.

Before we had our son, I could have never imagined the amount of time one child can occupy. We currently have at least four appointments a week, not including the large list of doctors that monitor him or the therapies that he needs each day. This practice is common for families with a special needs child and occupies a majority of my time. My friends may find I don't call as much as I used to, or, when I do, I may sound irritated and frazzled. Please understand that I still love you and need you in my life. In fact, I may need you more than I used to but am simply overwhelmingly busy and tired. Please, keep calling and keep offering your love and support.

## 3. I really do care.

This is kind of an extension of the point above, but something that I would like to make very clear. There are times when I am so tired that I have a hard time concentrating on what others say. Additionally, I may be so worried about something going on that I cannot concentrate on others in my life. Understand that I really do care about what you are saying. Doctors and therapists, please help me by writing down the important things that I must know and feel free to call and remind me if possible. Teachers please forgive me and help me stay on top of obligations regarding my other children. I try so hard to keep everything organized, but lots of things slip by. If you think that I am not listening to you, please try to understand it is not because I don't care.

## 4. My other children might need some extra support and attention.

It is so important to realize that the whole family is affected by major change. I try to help my kids with some of the obvious feelings that they have, but I know that there are a lot of things they would never tell me. Feel free to offer them support. Invite them over to do homework with your child – this activity would offer them support, attention, and be of great help to me.

### Especially for teachers and caregivers:

## 5. Above all else, love my child.

I appreciate everything that you do, I truly do. I also understand that sometimes we might disagree. Remember that in the end, the love that you have for my child matters to me most.

### Especially for doctors:

## 6. Be consistent!

An obvious statement, I know. However, my experience suggests that a doctor may optimistically offer a great deal of hope in the office for my child only to find just the opposite has occurred in a written report to another colleague. For example, my pediatrician gives me all written reports, because she feels it is my right to have them (I agree). The number of specialists that do not send us written reports astonishes me. Consider offering a summary report to your consumers regarding pertinent findings and be sure you are saying the same thing in those written reports as you do with the family.

## 7. Try to be positive.

I think that some people will see the last point and this one as opposite. I do not agree. I think that the doctor whom I spoke of above truly thought that he was just being positive. However, being positive involves pointing out the good things, not saying something that you don't believe.

## 8. Please understand you are not the only specialist we have.

Most children often attend only a single specialist. The particular problem he/she may be experi-

encing is probably a huge issue for the family of that youngster. However, when you have a child with multiple health needs, that is not the case. Please try to keep this in mind. We literally have a pediatrician and 11 specialists to juggle. Consider this before you send us for another test.

**9. Consider the guilt factor.**

Parents of children with special needs are often dealing with a great amount of guilt. The causes of many disabilities remain unknown. This parent questions everything that happened during that pregnancy, any issues that may appear as causation and listens to everyone who has an opinion—and there are many. Please consider this when you are dealing with a child with special needs. Are you about to report something that will add to that guilt? Maybe you should make that phone call instead of your nurse. Could there be another explanation that could help alleviate that guilt? If so, take the time to tell this family.

**Everyone:**

**10. Try to see beyond my child's disability.**

There is so much more to my son than his disabilities. He loves to laugh. He obviously loves his brothers. Try to see these things, and know that he adds so much to all of our lives. Try to see what he can add to yours. Trust me, it will be worth the effort!

**Footnote:** I hope that other parents can use this list. Maybe your list is a little different, but I have found that many of us share similar feelings. I hope that instead of letting things bother and hurt us, we can find a way to educate others about our beautiful children and how they change our lives.

**Without Sight, Rider Has Vision:  
Blind Teen to Compete Today, While Looking to Her Future**

By David Casstevens, *Star-Telegram* Staff Writer  
Reprint courtesy of the *Fort Worth Star-Telegram*

*Abstract: Learn how a teen with blindness competes with others on horseback.*

*Keywords: blind, horses, barrel-racing, parenting*

The horse knows the girl's voice. He knows her touch and the loving way she lays her cheek against his neck and feeds him treats from the palm of her small hand. Dollar also knows what 14-year-old Brittney Holland will ask of him when they compete today in the American Quarter Horse Association Youth Barrel Race at the Stock Show.

Horse and rider will bolt from one end of John Justin Arena, circle three drums in a cloverleaf pattern and race the clock to the finish line, Dollar at full gallop, cheered on by the crowd, the wind kissing Brittney's face and catching her long, blond hair.

Some say that seeing is believing. But one doesn't have to see to believe.

Brittney believes in her well-trained horse and in her skills and experience as a rodeo performer. The ninth-grade honor student from Aledo High School also believes what Susan Holland, her mother, has told her since she was 3. When Brittney asked if she would ever be able to see Hayley, her older sister, her mother told her no. "Britt, you're going to do greater things being blind than you ever would if you had total vision," Susan Holland said.

When Brittney was 2 months old, Susan and Greg Holland took her to a pediatric ophthalmologist in Fort Worth. The doctor examined the infant's teardrop-shaped pupils and explained that the backs of her eyes had not developed. Susan Holland didn't understand. "Are you telling me she needs glasses?" "Read my lips," the specialist said. "Your child is blind and will never see."

After the doctor walked out the door, the grieving mother sat in the exam room, cradling her baby, rocking her, weeping for her. She thought about her pregnancy and wondered if somehow she was to blame. *Was there something I did? Or should have done?* She felt frightened. Completely unprepared. *How do we raise this child?*

During the year that followed, Susan Holland experienced her own visual impairment, myopia: She couldn't see her daughter's future. "I was blind, too." The Hollands took Brittney to four other doctors. Each offered the same prognosis. At the suggestion of a vision teacher, the parents tried to stimulate Brittney's eyes by holding a metallic pom-pom before her face and moving it side to side and up and down.

Every two weeks they returned to a doctor. No improvement. No change. Susan Holland quit her job to help her daughter find her way in a darkened world. The family prayed. Their faith sustained them.

Over time, Brittney began to see just a little bit from her left eye. She could make out faint, blurred images — sort of like peering through a straw — and discern a contrast of colors. Her mother taped pink paper to the bottom of door frames to help the crawling infant navigate through the family home.

Susan Holland had competed as a barrel racer for 20 years. Both her daughters grew up around horses. Brittney wanted to ride because her older sister did, and when she was 4, Susan Holland fitted her with a safety helmet and put her on a horse, alone. A year later, the girl participated in her first barrel race, sitting atop an old, gentle horse named Doc.

Brittney wanted to ride faster and become competitive. When she was 8, her mother — also her coach — developed a communication system using walkie-talkies. Brittney wears her device clipped to her rhinestone-studded Western belt. She hears her mother's voice through an earpiece.

Susan Holland tells her when to loosen the reins. "Let him go!" When Brittney approaches a barrel — which she cannot see — her mother signals for her to turn by saying "Here!" If the instruction comes prematurely, the horse may strike the barrel and knock it over, incurring a penalty. Too late, and the wide turn costs Brittney seconds of precious time.

At 80 pounds, Brittney is no burden for the 1,300-pound animal beneath her. She has tumbled from the saddle in practice, but to her that's no big deal. We all fall. The trick is getting up.

Brittney can make out only two letters at a time in her large-print school books. To watch television, she must sit so close that her nose almost touches the screen. But she can see, far better than many others can.

She sees her future. Going to college — with Dollar — on a rodeo scholarship. Studying medicine. Becoming a veterinarian’s assistant.

“Good barrel!” her mother says in her ear.

The girl feels the horse’s strength and power. The speed of the final sprint.

“Nice run. ... Good run, Britt!”

## More to Life Than Meets the Eye

By Deborah Kent Stein

Reprinted with permission of *The Braille Monitor*, Vol. 42, No. 5, June, 1999,  
published by The National Federation of the Blind <<http://www.nfb.org>>

*Abstract: An adult with blindness tells about her decision to become a parent and the concerns about passing on blindness to a child.*

*Keywords: blind parent, relationships, parenting, inheriting blindness*

When I was only a few weeks old, my mother realized that I could not see. For the next eight months she and my father went from doctor to doctor searching for answers. At last a leading eye specialist confirmed everything they had already heard by then—my blindness was complete, irreversible, and of unknown origin. He also gave them some sound advice: they should help me lead the fullest life possible.

Fortunately for me this prescription matched their best instincts. As I was growing up, people called my parents “wonderful.” They were praised for raising me “like a normal child.” As far as I could tell, my parents were like most of the others in our neighborhood—sometimes wonderful and sometimes annoying. And from my point of view I was not like a normal child—I was normal. From the beginning I learned to deal with the world as a blind person. I did not long for sight any more than I yearned for a pair of wings. Blindness presented occasional complications, but it seldom kept me from anything I wanted to do.

For me blindness was part of the background music that accompanied my life. I had been hearing it since I was born and paid it little attention. But others had a way of cranking up the volume. Their discomfort, doubts, and concerns often put blindness at the top of the program.

Since one of my younger brothers is also blind, it seemed more than likely that my unknown eye condition had a genetic basis. I never thought much about it until my husband Dick and I began to talk about having a child. Certainly genetics were not our primary concern. We married late (I was thirty-one, Dick forty-two) and were used to living unencumbered. Since we both worked as free-lance writers, our income was erratic. We had to think about how we could shape our lives to make room for a child, whatever child that might be.

Somehow blindness crept into our discussions. I do not remember which of us brought up the topic first. But once it emerged, it had to be addressed. How would I feel if I passed my blindness to our son or daughter? What would it mean to Dick and to our extended families? What would it be like for us to raise a blind child together? I premised my life on the conviction that blindness was a neutral characteristic. It created some inconveniences such as not being able to read print or drive a car. But in the long run I believed that my life could not have turned out any better if I had been fully sighted. If my child were blind, I would try to ensure that it had every chance to become a self-fulfilled, contributing member of society. Dick agreed with me. We were deciding whether or not to have a child. Its visual acuity was hardly the point.

Yet if we truly believed our own words, why were we discussing blindness at all? I sensed that Dick was trying hard to say the right thing, even to believe it in his heart. But he was more troubled than he wished me to know. Once, when I asked him how he would feel if he learned that our child was blind, he replied, "I'd be devastated at first, but I'd get over it."

In retrospect I can appreciate the honesty of his words. Yet he had not given the answer I had wanted to hear. I was blind, and I was the woman he had chosen to marry, to spend his life with for better or worse. He accepted my blindness naturally and comfortably, as a piece of who I was. If he could accept blindness in me, why would it be so devastating to him if our child were blind as well? "You know why," was all he could tell me. "You have got to understand."

What I understood was that Dick was the product of a society that views blindness, and all disability, as fundamentally undesirable. All his life he had been assailed by images of blind people who were helpless, useless, and unattractive—misfits in a sight-oriented world. I had managed to live down those images.

Dick had discovered that I had something of value to offer. But I had failed to convince him that it is really okay to be blind. I wanted our child to be welcomed without reservation. I wanted Dick to greet its birth with joy. I did not know if I could bear his devastation if our baby turned out to be blind like me. In order to make a decision, we had to gather all the facts. Before we carried the discussion any further, we needed to find someone who could answer some critical questions.

On a sunny morning in October Dick and I set out to visit a specialist who had been recommended to us. Perhaps I would learn at last why I am blind. As we packed the car, Dick commented, "It's going to be a long, nervous day." I could not have agreed with him more.

I expected a battery of tests. But the doctor dilated my pupils, gazed into my eyes, and announced, "I'll tell you what you have, and I'm 100 percent certain. You've got Leber's congenital amaurosis." Leber's a genetic condition, he explained, autosomal recessive in nature. Both of my parents carried the recessive gene, and each of their children had a one-in-four chance of inheriting the eye condition. What were my chances of passing Leber's on to my own children? I asked. The doctor explained that I would inevitably give one recessive gene for Leber's to my child. But unless my partner happened to carry the same recessive gene, there was no possibility that our child would be affected. The chances that Dick would prove to be another carrier were slight.

The discussion could have ended with that simple exchange of information. But the doctor had more to say: "You have a good life, don't you? If you have a child with Leber's, it can have a good life, too. Go home and have a dozen kids if you want to." Even from a complete stranger, those were wonderful words.

The trip to the specialist cemented our decision to have a child. Days after our daughter Janna was born,

my mother and father flew out to visit us. Mom helped with the cooking and housecleaning while I marveled at the extraordinary new being who had entered our lives. I was too happy and excited to feel exhaustion. I was not worried about Janna's vision or anything else.

It was almost time for my parents to go home when Dick said to my mother, "You've raised two blind children. What do you think—can this kid see or not?" My mother said she really couldn't be sure. Janna was hardly a week old: it was too soon to tell. The day after my parents left, Dick found the answer on his own. As Janna lay in his arms, awake and alert, he moved his hand back and forth above her face. Distinctly he saw her turn her head to track the motion. She saw his hand. She followed it with her eyes.

"She can see!" Dick exulted. He rushed to the telephone and called my parents with the news. I listened quietly to their celebrations. I do not know if anyone noticed that I had very little to say.

How do I feel about the fact that Janna can see? I am glad that her world is enriched by color as well as texture and sound. And I am grateful that she will never be dismissed as incompetent and unworthy simply because she is blind. But I know her vision will not spare her from heartbreak; she will still meet disappointment, rejection, and self-doubt as all of us must.

For me blindness will always be a neutral trait, neither to be prized nor shunned. Very few people, not even those dearest to me, share this conviction. Sometimes I feel a sense of failure when I run into jarring reminders that I have not changed their perspective.

However, in recent years a new insight has gradually come to me. Yes, my own loved ones hold the unshakable belief that blindness is, and always will be, a problem. Nevertheless, these same people have made me welcome. Though they dread blindness as a fate to be avoided at almost any cost, they give me their trust and respect. I am not sure how they live amid these contradictions. But I recognize that people can and do reach out, past centuries of prejudice and fear, to forge bonds of love. It is a truth to marvel at, a cause for hope, and perhaps some small rejoicing.

## Looking Back and Looking Forward

By Kim Cunningham (mom to Kayleigh Joiner), Pearland, Texas

*Abstract: A mother shares her fears and joys, and describes the successes related to raising her child with a visual impairment.*

*Keywords: parenting, transitions*

*Editor's note: Kim's posting on the Texas VI Family listserv gives inspiration to families.*

I can remember 13-1/2 years ago when I was finally able to bring my little baby girl home from a 4-1/2 month stay in the NICU. She was born weighing only 1 lb. 7 oz. and left the NICU weighing 4 lb. 8 oz. My feelings were mixed with sadness and joy - joy at finally having her home and sadness in not knowing how to deal with raising a child with a vision loss. I was scared to death!

My greatest fear was that she would not know joy and she would not be able to lead a fulfilling life. I made a promise to her as a baby, that I would give her every tool she needed for success and the rest would be up to her.

Our family was joyous at every milestone; it didn't matter that she was delayed compared to her peers. I kept a close eye on what her next developmental step was and worked to achieve those goals. Throughout elementary school she struggled with concepts. I only asked her to do her best and never concentrated on what her grades were - sometimes it was an A - sometimes an F.

As she grew I saw a very determined little girl come to life. After trying for 5 or 6 years, she taught herself how to ride a 2-wheeled bicycle. Time after time, she fought to learn everything that her peers were doing – roller-skating, ice-skating, hitting a baseball, swimming and diving, and playing tennis. Nothing came easy for her!

This year, my daughter started her first year of junior high. Something happened that amazes me still - she blossomed into a child that is full of self-confidence. One of her class assignments in the fall was to state a goal for the year. Her goal was to make straight A's! After the first six weeks - she did it! It was her first time ever and we were elated!

As the year progressed, she continued making straight A's. I must admit that before every report card, I tried to prepare her for possibly making some lower grades as the subjects were getting harder. But it didn't happen. She glowed with pride in her success. Then, two weeks ago she brought home a paper stating that she was nominated by her teachers to be inducted into the National Junior Honor Society!

WOW - I cried my eyes out, all the while thanking God for blessing us with such great joy after so many years of uncertainty. I hope that this gives others the hope, when feeling hopeless, to never, never give up!

## **Kayleigh Has Her First Job!**

By Kim Cunningham, Parent, Pearland, Texas

*Abstract: A family takes a powerful step in path to success.*

*Keywords: volunteering, employment*

Last February, after our family attended Take Charge of Your Future, (a family transition workshop sponsored by the DARS Division of Blind Services and Texas School for the Blind & Visually Impaired) I came home feeling very empowered about Kayleigh's future. Not only was my husband and I empowered, but also Kayleigh was empowered in knowing the choices that she had for her own future.

We have always talked about going to school, getting good grades, and then going to college somewhere. What we failed to discuss was the training that she would need to prepare her for employment, transportation, housing issues, or resources for assistance. The workshop gave us a wonderful plan on volunteering in our community.

The goal was for Kayleigh to learn how a business operates and what it is to be an "employee". Our school year is hectic with homework and extracurricular activities, so our actions were a little late in getting started.

Kayleigh weighed out her options on which business she would like to apply to volunteer. She decided that our community library would be her choice after seeing a sign requesting volunteers for the Summer Reading Program. Kayleigh filled out her application with minimal help and then waited for a call.

Last week, in preparation for being accepted, we met with her O&M teacher at the library to orient her with the facility. It was during this time that we were finally able to meet with the children's librarian. Kayleigh was very nervous, but handled the conversation with a lot of maturity. She briefly told about her visual impairment and the tools that she had to complete the required tasks. The librarian didn't hesitate one moment before telling her she was looking forward to working with her this summer.

Update from Kayleigh: My volunteer job is going well. I help sign kids up for the summer reading program at the library. I give them a certain form: either a time form if they want to read for four hours or more, or a title form if they want to read ten books or more. They also have to fill out an enrollment card, which has to be alphabetized by their last name. I am enjoying it a lot, and I hope to do some more work next summer.

## **Transition Matters: Yikes! Consider Life Without School! Planning Now for a Good Life for Your Child with a Disability**

By Rosemary Alexander, Texas Parent to Parent Volunteer and Mom to Will, Austin, Texas

*Abstract: A parent shares helpful strategies families can use to create a meaningful life after their child with special needs graduates from school.*

*Keyword: parenting, transition, futures planning*

Think of the benefits your child receives from the school system: a safe place to be all day, with opportunities for learning, enrichment activities, behavioral supports, exercise, nursing support, contact with caring adults besides yourself, structure and routine, job training and experience, and friendship. And it's free. And a law mandates school services, based on a plan created with your input.

Now picture your child's life devoid of these opportunities. That's life after graduation—nowhere to go, nothing to do, no friends, no assistance, no plan, no voice, no free activities! Wow! Get scared now.

How can you and your family work now to create opportunities for work, friends, and meaningful activities for your child after graduation?

1. Start now, whatever the age of your family member with a disability. Get over your fears, denial, inertia, ignorance, or whatever is keeping you from facing this issue. Focus on what your child needs.
2. Get your child's name on the waiting lists for community supports; these lists have an 8 to 10 years' wait.
3. Learn about other community supports and services for adults in your community, such as Resource Centers for Independent Living, MHMR, DARS (TCB), The Arc, SSI/Medicaid. Find out what your child is eligible for and how to access these services and supports. Become knowledgeable about other important transition issues: guardianship and power of attorney, estate planning, the school-based transition process. Be prepared for each step.

4. Realize that public funding does not guarantee a good life. Do not depend on these services for everything; here's where bold thinking, planning, creativity and collaboration come in.
5. Create a plan: sit down with your child, other family members, friends, anyone who knows your child, and brainstorm together about the future. There are several planning tools out there, such as Person Centered Planning. Using this approach, ask your son or daughter: what do you like? What do you dislike? What are you good at? What are your talents and strengths? What supports do you need for living and working? What are your dreams for the future? Write down his or her responses and include the comments of the other participants. Then write an action plan for one of the dreams or goals the group has identified. These goals could be anything, lose 20 pounds, get a job, find a friend, move into an apartment, learn to read. It doesn't matter as much what the goal is as the process of gathering a group together and talking about the future. Most goals lead back to the basics and will move you along toward the future. Remember to encourage your child to participate as much as he can; if he is nonverbal, the group must speak on his behalf, as you imagine he would speak if he could. Siblings are often great at this and everyone enjoys being asked to speak up.
6. Teach your child to speak up for herself, to be a self-advocate. IEP meetings are a great place to practice advocacy skills: your child might start by introducing the people around the table and eventually become able to discuss goals and services. These skills will assist her to get the help she needs when you are not around to speak for her.
7. Be sure that your child is learning social skills wherever opportunities arise
  - at home, at school, at church
  - wherever he is with people. Getting along with people and building friendships are the most important skills we acquire through life—these skills usually make the difference between keeping a job and losing a job, between an isolated life and a life of meaning and fulfillment. Also be sure your child is learning to play—what activities do his peers participate in? Could your child learn to do them? Activities, interests, and hobbies often provide the best opportunities to build friendships.
8. Be sure that your child is learning job skills. Give her chores to do at home; as she gets older, perhaps she can volunteer in the community. Be sure the school is providing vocational training and experience in secondary school. Help your child learn to take responsibility, show up on time, get along with the boss, acquire the skills needed to get and keep a job. Even people with the most profound disabilities can work in some capacity. And work is another way to add meaning to life and find friendships.
9. Build networks for your child. Find people to involve who might be willing to take on some of the roles that you now fill in your child's life. Remember, no school services! What will your child do and with whom?

And build networks for yourself. The transition process is hard emotionally, as you face your fears about a time when there are no school supports and even the time when there's no you! Letting go of these children whom we have worked so hard to raise, protect, and figure out is not easy; we have invested so much emotionally by going through grief, shattered hopes, trial and error, that sometimes it's hard to stop doing it all for them. Find other parents going through this transition and build supports for each other. Perhaps together you can build a good life for your children!

10. Picture a life for your family member with a disability that you yourself would enjoy living. Our dreams help us to keep our children from empty lives. So imagine your child as an adult living a “good life:” living in a place you would like to live, working, participating in the community, with opportunities for friends, fun, fitness, surrounded by people who care about him. Then start to work to make this a reality!

Now you are probably feeling quite overwhelmed. So take a deep breath and prioritize. You don’t have to do it all at once. Start by getting your child’s name on the waiting lists, then start educating yourself. Consider what needs doing now, what’s most important for now. And keep reading this column for more concrete advice on planning for the future.

### **Transition Matters: My Own Transition Story**

By Rosemary Alexander, Texas Parent to Parent Volunteer, Austin, Texas

*Abstract: One parent shares her experiences in creating a meaningful life for her adult son with special needs.*

*Keywords: parenting, transition, futures planning, personal experience*

At my house we are through the first year of PG—post graduation. My son Will graduated from public school last May, soon after his 22<sup>nd</sup> birthday, and this past April he turned 23. It’s not been an easy year, even though we in Will’s life planned and worked hard for PG, but I have learned a lot about what’s working well and what is not, and I feel hopeful about the future! Hope is a rare commodity in this transition experience, so I’d like to share our story to give you some hope—and some ideas.

First I’ll tell you about Will. He has a great smile, an infectious laugh, and a slapstick sense of humor. He walks, though he falls easily. He learns routines over time and likes to be active. He enjoys riding an adapted 3-wheel bike, scribbling with paints and pens, and doing chores with another person’s help. He likes to give you something and get lots of praise in exchange. He loves to feel included and hates feeling excluded. He “gets” situations, quickly figuring out what’s going on and who might prove to be a friend. Assets in his pocket are a caring family and a funding source (one of those community supports that you have to wait 10 years to get). He does need lots of help—he doesn’t read, write or talk. He has had a terrible seizure disorder and must get his medications 3 times a day. He is not safe alone and needs help with eating, dressing and toileting.

When Will was a young teenager, I began to wonder what he would do “down the road.” At first, I pictured him in a group home, but absolutely not an institution. Those were the only 2 choices I knew about. Then I heard an Austin Travis County MHMR speaker say that group homes, as we have known them, are being phased out. I felt shocked and very angry with the system. Does that mean Will should live with us forever? I love Will and enjoy his company, yet I knew that I couldn’t provide his care forever. I also knew that I couldn’t let him live without high-quality care and people around him who enjoyed his company. I was feeling very pessimistic.

The year Will turned 18 was busy: we got guardianship for him, we signed him up for SSI/Medicaid, and we realized that “down the road” was nearly here. As I worried, I happened on a book called *A Good Life*, by Al Etmanski, and for the first time I could see a way through transition. The author of this book, with his wife Vickie Cammack, started an organization around 1990 in Vancouver, Canada, that helps parents answer the question, what happens after we die? How can we provide on-going support for my child with a disability after we’re gone? The first chapter talks about facing your own death. The second is about building a personal network for your child. The remaining chapters each focus on one major area of life: a home, work, financial planning, and guardianship. The book is full of stories about people who, with PLAN’s help, created personal networks for their family members with a disability and worked creatively on other issues for adulthood. I was hooked.

I gained from this book a sense of higher expectations that we don’t have to merely take what the government system provides but can dream of a life that suits Will. Then I had to think about what that life would look like, a realization that led me to person-centered planning. I found a facilitator in my school district to facilitate our planning sessions and invited 8 people to help us plan, my brother and his wife, an OT who had worked with Will, his job coach from school, some family friends, and our own family, myself and Bill and our son Randall. We met 3 times over 6 months, going through a series of questions about Will’s interests and strengths and then formulating our goals for him. Then we created an action plan for each goal and worked on each action plan.

One of our goals emerging from these sessions was to create a personal network, as described in *A Good Life*, so before long, we had turned the planning group into a long-term network. Networks are for anyone who is at risk of isolation. You invite a group to meet regularly and become friends with one another and the person with a disability. The group stays involved, taking on various roles for the focus person, working to enrich and protect the life of the person with a disability. When a member has to leave the network, the group finds someone else to replace that person, thus ensuring longevity. Our network has met now about 4 times over a year. We meet at our house and eat together, talk about Will’s issues and celebrate our shared lives. I think of this group as the keepers of his person-centered plan, responsible for seeing that he gets to do what he likes best and can avoid the things he doesn’t like, that his dreams will continue to be our focus, that we base our decisions about Will’s life on his dreams, his joys and strengths. It is a remarkable feeling to know others are willing to become involved in Will’s life and care about his well-being. And the biggest fan of Will’s network is, of course, his brother!

One other step I have taken is to write down what I know about Will—his medical history, how he communicates, how to work with his behaviors, what food he likes, what shoe size he wears, where I buy his shoes, and much more. I have given a copy of—“Welcome to Will’s Life” to his network members. The notebook continues to grow and change as Will changes.

Now at age 23 Will works a few hours each week, delivering mail at a seminary and delivering sandwiches at two schools. (Remember that he likes to give you something and get lots of praise in exchange?) He goes swimming once a week, attends a few activities and classes and does all these things with an attendant paid by CLASS. He seems to have moved from school to life beyond school pretty well. There are times when an activity hasn’t worked out, sometimes he misses an activity because the attendant is ill, and perhaps he doesn’t have enough to do. It’s not easy to put together his life and I still feel that my system for him is fragile—there is no backup plan. I meet regularly with a group of parents who are trying to create a home together for our

children, where we would share resources and costs and (I hope) create a more stable system for our children. But today Will has fun, seems healthy and stays active. It's a work in progress. And I have hope that we can continue this journey and build a secure, quality life for Will.

One more step that I've taken was going to Vancouver in March of this year to attend a PLAN institute. I've come back to Austin eager to start a PLAN-like organization here and I've been welcomed into Texas Parent to Parent to create a center here focused on a quality life for our family members with disabilities. Good luck in writing your own transition story.

Editor's note: The book Rosemary used as a road map for writing her own son's transition story, *A Good Life*, is available at <[www.plan.ca](http://www.plan.ca)>. Rosemary will continue to write for the Texas Parent to Parent newsletter on transition issues, which can be found <[www.main.org/txp2p/](http://www.main.org/txp2p/)>. If you are interested in learning more or wish to start some of the PLAN's ideas in your area, please contact Rosemary by calling Texas Parent to Parent at (866) 896-6001.

## **Postsecondary Education: Preparation Is a Necessary Ingredient for Success**

By Deborah Leuchovius

Reprinted with permission from the Summer 2004 issue of the *PACESETTER*, a publication of the Pacer Center, Inc., Minneapolis, Minnesota, (952)838-9000.

*Abstract: This article describes the skills needed by students with disabilities to prepare for postsecondary education.*

*Key words: blind, visually impaired, deafblind, parents, transition, postsecondary education, college, study skills, self advocacy*

Research shows that completing some type of postsecondary education, including vocational-technical training leads to higher earnings, higher self-esteem, more meaningful employment, and economic self-sufficiency.

More and more students with disabilities are going on to college. Unfortunately, most students with disabilities who go on to higher education leave before they complete their program or degree.

If students with disabilities have higher education as a goal, it is critical that they leave high school with the skills they need to be successful there. Through the transition planning process, parents and educators can help ensure that a student's secondary education program provides a foundation for postsecondary success. A student on an individualized education plan (IEP) should have a transition plan included at age 14. The plan can include postsecondary goals.

### **KEYS TO SUCCESS**

What exactly are the skills students need to be successful in higher education? Adequate academic preparation, self-knowledge, self-advocacy, study skills, time management, and perseverance. In addition, the tran-

sition team should help students collect the documentation they will need to obtain services in college and plan for financial aid.

## **ADEQUATE ACADEMIC PREPARATION & STUDY SKILLS**

Staying in college is difficult without a solid academic foundation. One of the greatest barriers to college for students with disabilities is the lack of a strong academic preparation. Students with disabilities are less likely to complete a full academic curriculum (differences are most significant in math and science) than students without disabilities. The result is that they are far less likely to qualify for admission to a four-year college.

For many students this comes as a surprise rather late in the game. It is not until college entrance exams reveal what students lack in their academic knowledge that many discover they will have to take remedial courses.

Early planning is the best way to ensure success. A student's courses should include college preparatory courses—in middle school or junior high, as well as in high school. If your son or daughter expresses an interest in postsecondary education, make sure they understand the classes they will need to take and the grades they will need to maintain in order to qualify for admission. Students should talk with teachers and counselors to map out a curriculum that corresponds to the admission requirements of state colleges.

For many students, it is disorganization, not the learning material that makes getting good grades difficult. Parents can help students to develop good study and time management skills. Good study skills involve setting goals; being organized; and setting a place, time and schedule that is study friendly.

High school students intending to continue their education should also practice using postsecondary-type supports in their general education classrooms, for example, low tech assistive technology such as talking books, specialized tape recorders, and portable note-taking devices.

Colleges look for well-rounded students. Becoming involved in extracurricular activities such as sports, community service, music, or drama may help students enter more competitive college and university programs.

## **SELF ADVOCACY**

It is not just the academics that are difficult in postsecondary education. Postsecondary schools expect students with disabilities to take the initiative, to declare their disability, and to work with the disability support personnel to plan their accommodations. In addition, accommodations must be negotiated with each instructor.

It is absolutely essential that students with disabilities going on to college develop the following in the course of their high school education: 1) a basic understanding of their disability, 2) knowledge of the accommodations they will need in post-school environments, and 3) the ability to articulate both of these things to others.

Attending their own IEP meetings and being active in the planning and implementation of their own educational plans is a beginning step in developing these skills.

## Formal Versus Informal Hearing Tests: What Is Functional Hearing?

By Jim Durkel, CCC-SPL/A, Texas School for the Blind and Visually Impaired Outreach  
(with help from and thanks to Kate Moss, TSBVI Outreach)

*Abstract: This article defines the difference between formal audiological hearing tests and functional, or informal, hearing tests and describes how information from these assessments can be shared to meet the needs of a child.*

*Key Words: programming, audiological test, functional hearing, auditory functioning, deaf, deafblind*

The term functional hearing is being used more and more often these days. What does it mean? What is functional hearing and how is functional hearing determined?

Formal audiological tests stand in contrast to “functional” tests of hearing. This is a bit misleading and unfair to standard tests since they can give a great deal of information about the functioning of the auditory system. A better distinction might be formal versus informal. This informal process is a way of gathering information about how students use their hearing to gather information and how they make meaning out of this information in different environments across the day.

### FORMAL AUDIOLOGICAL TESTS

There are 2 major categories of formal audiological testing: physiological tests and behavioral tests.

#### Physiological Tests

Physiological tests include auditory brainstem response testing (ABR or BSER), oto acoustic emission audiometry (OAE), and tympanometry. These tests are functional in the truest sense of the word: they describe the neurological or mechanical functioning of the auditory system. They do not involve active participation of the person being tested. Audiologists can hypothesize about how results on these tests will affect an individual’s use of auditory information but there is not an exact one-to-one correspondence between neurological or mechanical function and what an individual can and can not do with his or her hearing.

#### Behavioral Tests

Behavioral tests require the participation of the individual being tested. The most common behavioral tests involve pure tones. Pure tones are sounds generated by a machine. These sounds are very controlled for their pitch and loudness. Pure tones do not exist in nature. Even individual musical notes are not pure tones. All natural sounds, especially speech, contain a combination of different frequencies (pitch) of varying intensity (loudness). During pure tone testing, audiologists are trying to find an individual’s threshold at various frequencies. Threshold is the intensity level where a sound can just be detected. There is not an exact one-to-one correspondence between auditory thresholds and what an individual can do with her or his hearing, but pure tone testing is important to use as a starting point for predictions and to use as the basis for hearing aid fitting. Procedures very similar to pure tone testing are also necessary for the fitting of cochlear implants, during the procedure known as mapping.

Pure tones can be delivered to the ear either through the air, by using headphones or speakers, or through bone conduction, which involves a special vibrator being placed on the head. Differences in air conduction and bone conduction thresholds give information to audiologists and doctors about what part of the auditory system might be having difficulty.

There is another type of behavioral testing that many students with deafblindness never have administered. Instead of using pure tones, speech is used. Using speech, an audiologist can determine:

- a speech detection threshold (how loud speech needs to be for a person to just detect it),
- a speech reception threshold (how loud a special type of 2-syllable word needs to be before an individual can correctly identify a specific proportion of them), and
- speech discrimination (what percentage of words at a fixed loudness an individual can correctly identify).

Unfortunately, the measure that is the most like “the real world”, speech discrimination testing (especially when done in the presence of noise), is also the most difficult. This is because the individual who is being tested needs to be able to repeat words, write words, or point to pictures of words. Speech discrimination testing is very important to good hearing aid fitting and in the on-going adjustment of the speech processor component of a cochlear implant. Many children with significant multiple disabilities are not able to participate in speech discrimination testing.

Again, there is not an exact one-to-one correspondence between these formal audiological tests and every day use of hearing. Then why do these tests?

Both physiological and behavioral tests were designed to give specific information about the auditory system. The conditions under which they are given and the type of input used is carefully controlled so that results of one person’s tests can be compared to another person’s tests. And so that performance on a test one day can be compared to performance on the same test on another day. This gives us the opportunity to talk about the integrity of the auditory system with as little regard to other factors, such as cognitive or physical ability, as possible. The advantage of this is that we can identify where in the auditory system a problem might exist. This has very important medical implications and for this reason alone **formal audiological testing should never be replaced with informal testing**. The two kinds of testing are complementary.

Formal testing allows for the careful evaluation of hearing aids and the adjustment of cochlear implants. Finally, while pure tone testing done in an audiological test booth is a different listening situation than trying to carry on a conversation in a car, pure tone tests can give a ballpark prediction of the success of that conversation. Physiological and behavioral tests give us a very important starting point.

## LISTENING IN THE REAL WORLD

What is it about “real world” listening situations that make predications from formal tests inexact? There are three factors to consider: the source of the sounds, the environment, and the listener.

### Sound Sources

Sound is not simple and speech, the sound we often are most interested in, is the most complex. Speech contains a mix of sound energy at different frequencies and this information changes very rapidly. This mix and these changes allow us to hear the difference between the various vowels and consonants. We then have to assign meaning to the speech sounds we hear. This takes cognitive ability. Finally, to create those sounds ourselves takes motor ability and then auditory ability again as we monitor our own speech.

It is important to understand that being able to detect a sound is a different skill than being able to discriminate a sound. I may be able to hear the presence of a sound because it contains energy in a range my auditory

system can handle. But if my auditory system can't give me the whole picture, if I can't hear all the energy in that sound, I may not be able to hear how it is different from another sound. Talking over the telephone is an example of this. Telephones do not allow the full range of sound energy to go through. Some high frequency information is taken out so that the telephone can work more quickly. This is why the word "fin" can easily be confused with the word "sin", or "thin". You can "hear" (detect) the word but have trouble discriminating (understanding exactly what is heard).

A person with enough speech and language experience, often can "fill in" pieces of what was not heard. For example, someone may call to me from another room and all I can hear is, "Do you have the \_og?" Now if I know the other person is trying to light a fire in the fireplace, I will fill in the blank and "hear" log. However, if I have just been petting my German Shepherd, I will probably "hear" dog. This effect of experience and context on hearing is just one reason why formal tests don't predict use 100%. Experience also helps us interpret other sounds we hear. Before cell phones were common, how many of us knew what those sudden noises coming out of nowhere meant? Why would I pay attention to a doorbell if I grew up in a house that only had a doorknocker? I always think Harley Davidson motorcycles sound like they are broken. This is because they normally sound like my car does when its muffler has fallen off. How many of us think rap music is noise but rock and roll is here to stay?

### **The Environment**

The environment in formal audiological testing is very controlled. Typically, there is little competing visual or tactual information and the room is treated to eliminated noise and echo. Now think of a child's typical listening environment where there are all kinds of competing sights, sounds, smells, and touches. Some children may get so neurologically "distracted" by what they see that they appear "deaf" in typical listening environments but appear to hear just fine in formal testing environments. On the other hand, it is not uncommon for a listener to use other senses to help support and confirm what was heard. For example, people with Usher syndrome often think their hearing is getting worse when really the hearing loss is stable and it is their visual skills that are declining. These individuals have been using visual information to support their hearing for so long they are unaware of doing so.

### **The Listener**

Finally, there is the listener. Part of the "art" of formal behavioral tests is discovering how to motivate a listener to participate in what is a fairly boring, uninteresting task. The formal testing situation may be so unfamiliar to the child being tested that it is scary. Formal testing may be associated with unpleasant experiences in a doctor's office. The amount of time allotted for the testing may be too short to allow the child to be comfortable or so long that the child's participation wanes. The time of day of the testing appointment may not be the time that the child is the most alert. Formal testing often treats the child as if he or she were only a pair of ears and ignores the rest of the child.

## **THE INFORMAL HEARING ASSESSMENT PROCESS**

The goal of informal hearing process is to:

- develop an idea of how the child uses his or her hearing in various environments across the course of the day; and
- try to discover what variables support the best use of hearing in order to continuously improve the use of hearing.

During the process, observation will be used to determine what, if any, sounds the child seems to react to and what, if any, meaning the child is getting from auditory information. Observation, of course, is also supported with information from formal hearing tests. Observation also includes setting up situations and seeing how the child responds.

### **Step 1: General Functioning**

The first step of informal hearing assessment is getting an idea of the general functioning of the child.

- Does the child show any awareness of any sensory information (visual, tactual, etc.)?
- How does the child show that awareness?
- What motor behaviors seem to indicate that the child was aware of and responding to sensory information?

Without this information, you can't tease out hearing from other factors.

Good questions to ask at this point are:

- What does the child do with sensory information?
- Has the child learned (or can she learn) to associate movement cues with a pleasurable activity?
- Does the child show anticipation of an event from seeing or touching an object?

### **Step 2: Responses to Auditory Information**

Now you can ask:

- Does the child show anticipation or recognition through the use of hearing? That is, does the child anticipate an event when they only hear a sound associated with that event (before they see or touch something associated with the event)?
- What sounds does the child respond to?

### **Step 3: Looking for Patterns**

At this point, we are looking for patterns of responses. We are trying to find out which sounds under what conditions give the best (easiest to see, most consistent, meaningful to the child) responses.

- 1) Is there a difference in performance based on the types of sounds?
  - low pitch vs. high pitch
  - onset vs. cessation
  - simple vs. complex (for example, one instrument vs. orchestra)
  - rhythms
  - loud vs. soft
  - long vs. short (duration)
- 2) Are there any clear preferences?
  - people's voices (male/female, young/old, familiar/unfamiliar)
  - types of music
  - musical instruments
  - objects

- 3) Is there a difference in performance in different environments?
  - quiet vs. noisy
  - echo
  - competing (or supporting) information from other senses
- 4) Is there a difference in performance depending on where the sound comes from?
  - in front
  - behind
  - right
  - left
  - above
  - below
- 5) How long after the input does it take for a typical response to occur?
- 6) Do responses vary
  - across different environments? (indoors, outdoors, hallways, carpeted room, tiled rooms, etc.)
  - at different times of day?
  - before or after meal time?
  - before or after receiving medication?
  - with the physical position of the child?

Natural observation (doing nothing but watching the child) might not give you all the information you need at this point. Using information from formal hearing tests, you might want to set up some situations to help you observe patterns. For example, the results of formal hearing tests may indicate that the child should be able to hear loud low frequency sounds, like a drumbeat. You then might want to set up a simple turn taking game involving the beating of a drum to see if the child will listen while you beat a drum then take a turn and beat a drum after you stop. If the child can do this, then you might want to try similar games with other sounds that vary by pitch and loudness to see what sounds the child can use and which he or she can't. Of course, it may take several repetitions of the game, across several days or weeks, before the child learns their role.

#### Step 4: What Does It Mean to the Child?

The next step is to ask, "How does the child use auditory information?"

- At a reflexive, awareness level? Does the child startle to sound but otherwise not pay much attention?
- At a regulating level? Does sound help the child enter and maintain a quiet and alert biobehavioral state? Are there sounds that send the child into a fussy, agitated state?
- At a motor level? Does the child turn towards or reach for an object or person making a sound, even if the child can't see or touch the sound source?
- At a play level? Does the child enjoy making noise, either with his or her mouth, by activating switches, hitting two objects together, playing musical instruments, etc.
- At an associative level? Does the child associate a particular sound with a particular event?
- At a communication level? Does the child recognize any common words, especially his or her name? Does the child try to use any sounds consistently to communicate?

## Step 5: Where Do We Go From Here

Gathering this information over time can help guide programming for the child. Information from steps 1-4 should give an emerging picture of what is meaningful to the child. This information should guide our next steps: that is, how do we help the child use a greater and greater variety of auditory information in more and more situations and with better precision and in more and more sophisticated ways. Informal information should be shared with audiologists to help them in the process of deciding how well a hearing aid or cochlear implant is meeting the needs of a particular child and if adjustments need to be made. Information from the informal hearing assessment process can also help guide the formal hearing assessment process by letting the audiologist know typical kinds of responses a particular child might make to various kinds of auditory input.

## RESOURCES

There is a book, *Every Move Counts*, by Jane Korsten (Therapy Skill Builders, 1993) that outlines a process that can be useful for gathering information. *Every Move Counts* deals with all the senses, not just hearing.

Another soon to be released product that helps look at how a child uses sensory information is the “Sensory Learning Kit”, (Millie Smith, primary author) from American Printing House for the Blind. This product should be available sometime in 2006.

Finally, at <http://www.tsbvi.edu/Outreach/deafblind/process.htm> is “A Process for Identifying Students Who May Be At-Risk for Deafblindness”. This is a collection of information and downloadable forms that can be used to support the gathering of information in an informal way.

Teachers for the deaf and hard of hearing typically have training to help look at auditory functioning in this informal way. They may be a valuable resource in this process.

## What’s with the Wax in Your Ears?

By Kate Moss, Education Specialist, Texas Deafblind Outreach

*Abstract: This article is about the importance of investigating the correctable problem of earwax buildup in visually impaired and multiply impaired children so that functional use of their hearing is maximized.*

*Key Words: Programming, ear wax, ENT*

There are a variety of problems that can result in hearing loss. Deformities in the outer part of the ear or in the middle part of the ear can result in a conductive type of hearing loss. Fluid in the middle ear or an obstruction in the ear canal may also cause this type of hearing loss, which is typically mild to moderate and can typically be easily corrected. A mild to moderate hearing loss during critical periods of language development can greatly impact the child’s speech and language development. When the child is also visually impaired, having a mild to moderate hearing loss that goes uncorrected is a big deal.

Any child with visual impairments, but especially those with multiple disabilities needs to make good use of their hearing to learn many of the things they need to know in life and to accommodate for their reduced visual capacity. Children who are blind or visually impaired have only one reliable distance sense and that is

their hearing. The development of good auditory skills is critical to learning in general and especially important for literacy. Orientation and mobility skills depend in part on using auditory cues and landmarks to know where you are in space. Special care should be taken with visually impaired or blind students to make sure there are no problems with hearing.

One problem that is often not considered, especially in a child with multiple disabilities, is a problem with earwax build up. Everyone's ears produce earwax or cerumen. This yellowish wax is produced by glands in the ear canal and helps to keep the ear canal clean and healthy. The movement of the mouth and jaw help the wax to move out of the canal naturally, carrying with it dust, dirt, and dead skin cells. Sometimes, however, the wax becomes very hard and gets packed into the canal. When this happens, the effect is like putting in ear-plugs. Water may also become trapped behind the wax and create more problems. Because sound cannot get into the ear efficiently the person may experience a mild to moderate hearing loss. This may also cause a feeling of fullness in the ears, dizziness or even tinnitus (a ringing in their ears).

Some people naturally generate a great deal of earwax and some people are inclined to have wax impaction problems. But many people create wax impaction problems by pushing the wax into the ear canal as they attempt to clean it out of their ears with cotton swabs, pins and the like. Attempting to clean out earwax in this way can also result in eardrum perforations, infections in the ear canal, and/or dry, itchy ears. It is good rule to simply clean out the ears using your finger and a washcloth.

Children should be checked periodically for earwax build up. This can be done with an otoscope by the child's pediatrician or ENT and may often be done as part of a regular physical. If there is a wax build up, the doctor may prescribe or suggest an over-the-counter drop to help remove the wax. If necessary he may need to remove the wax with warm water and a syringe, scrap it out with a curette, or use a device to suction it out.

Take note of how your child seems to use hearing, especially if he/she is visually impaired. Do there seem to be problems in certain situations? If so, make sure the doctor checks for problems with earwax buildup or other concerns. It is probably a good idea to have regular and periodic hearing tests done, even on your child with multiple disabilities. Hearing is too important a sense to allow correctable problems with hearing to go uncorrected.

### **The Sense of Smell: A Powerful Sense**

by Gloria Rodriguez-Gil, M.Ed., California Deaf-Blind Services Educational Specialist  
Reprinted from *reSources*, Spring 2004, Volume 11, Number 2 with permission from  
California Deaf-Blind Services <<http://www.sfsu.edu/~cadbs>>

*Abstract: This article is about how the sense of smell works and how this powerful sense may impact programming in the field of deafblindness.*

*Key Words: programming, deafblind, smell, senses*

Several years ago I was shopping at Macy's in New York when suddenly I smelled something familiar, and I immediately thought of my childhood doll Lucy. You see, I had not thought about Lucy for years, much less that Lucy had been my favorite doll back when I was growing up in Spain. Looking around, I realized that I was in the store's toy section and that I was very close to a stand of dolls. Out of curiosity, I reached out for one of the dolls. On the doll's box it said: "Made in Spain".

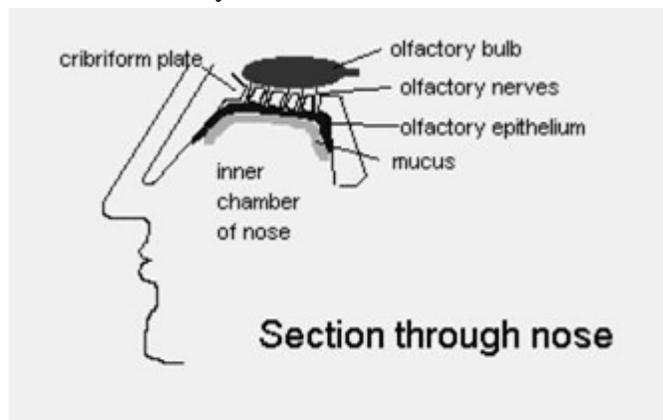
This experience was incredible to me—that something so far back in my memory could be brought to the present by something so fleeting as one smell! Years later I recalled this incident when I learned that the part of the brain responsible for our sense of smell—the limbic system—is related to feelings and memory.

In order to make sense of what smell is and how we can think of using it in our work, let's first explore how the sense of smell is put together.

## HOW THE SENSE OF SMELL WORKS

The sense of smell, just like the sense of taste, is a chemical sense. They are called chemical senses because they detect chemicals in the environment, with the difference being that smell works at dramatically larger distances than that of taste. The process of smelling goes more or less like this:

1. Vaporized odor molecules (chemicals) floating in the air reach the nostrils and dissolve in the mucus (which is on the roof of each nostril).
2. Underneath the mucus, in the olfactory epithelium, specialized receptor cells called olfactory receptor neurons detect the odor. These neurons are capable of detecting thousands of different odors.
3. The olfactory receptor neurons transmit the information to the olfactory bulbs, which are located at the back of the nose.
4. The olfactory bulbs has sensory receptors that are actually part of the brain which send messages directly to:
  - The most primitive brain centers where they influence emotions and memories (limbic system structures), and
  - “Higher” centers where they modify conscious thought (neo-cortex).
5. These brain centers perceive odors and access memories to remind us about people, places, or events associated with these olfactory sensations.



Picture taken from <<http://www.cf.ac.uk/biosi/staff/jacob/teaching/sensory/olfact1.html>>

It is important to add that “Our sense of smell is 10,000 times more sensitive than any other of our senses and recognition of smell is immediate. Other senses like touch and taste must travel through the body via neurons and the spinal cord before reaching the brain whereas the olfactory response is immediate, extending directly to the brain. This is the only place where our central nervous system is directly exposed to the environment.” (von Have, Serene Aromatherapy)

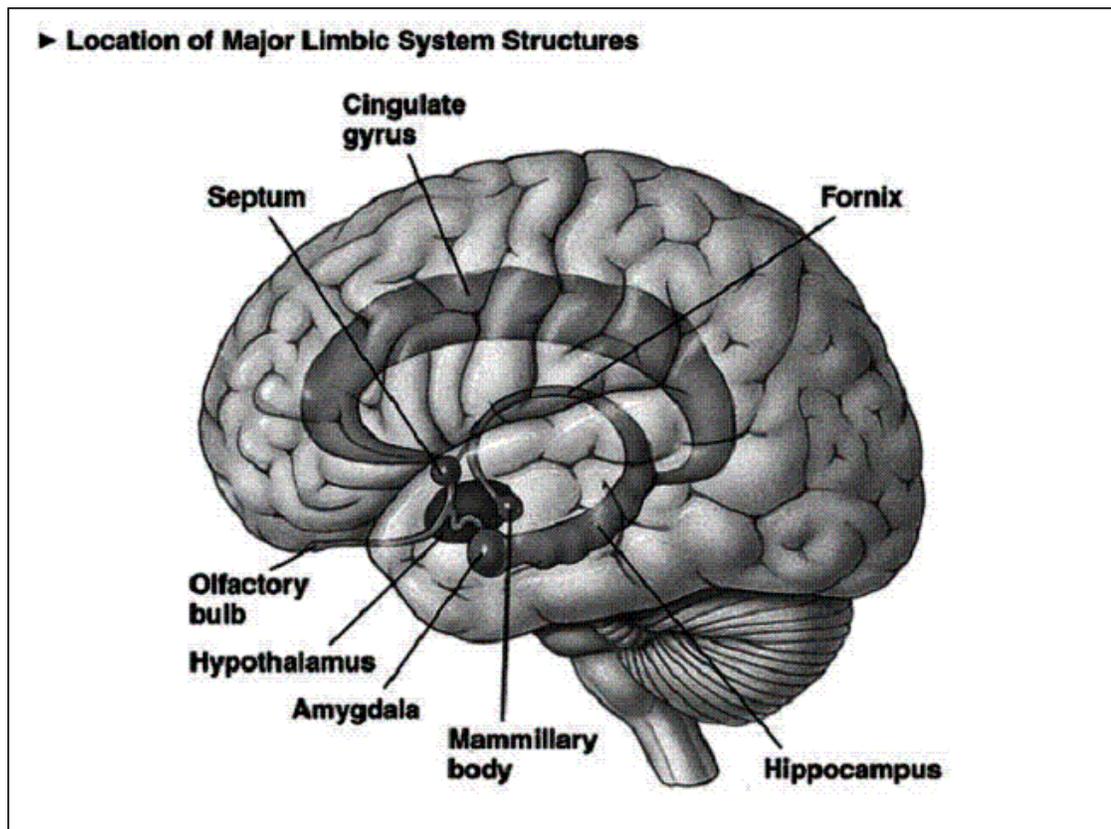
## THE SENSE OF SMELL AND THE LIMBIC SYSTEM

The olfactory bulb is one of the structures of the limbic system and a very ancient part of the brain. As mentioned in the previous description of the olfactory process, the information captured by the sense of smell goes from the olfactory bulb to other structures of the limbic system.

The limbic system is a network of connected structures near the middle of the brain linked within the central nervous system. These structures “work together to affect a wide range of behaviors including emotions, motivation, and memory” (Athabasca University-Advance Biological Psychology Tutorials). This system deals with instinctive or automatic behaviors, and has little, if anything, to do with conscious thought or will.

The limbic system is also concerned with translating sensory data from the neo-cortex (the thinking brain) into motivational forces for behavior. The limbic system is centrally involved in the mediation between a person’s recognition of an event, their perception of it as stressful, and the resulting physiological reaction to it, mediated via the endocrine system: Stimuli are processed conceptually in the cortex, and passed to the limbic system where they are evaluated and a motivational response is formulated.

PROGRAMMING



Picture taken from <[http://www.driesen.com/the\\_limbic\\_system\\_-\\_2.htm](http://www.driesen.com/the_limbic_system_-_2.htm)>

### WHAT DOES THIS HAS TO DO WITH OUR FIELD?

In the field of deaf-blindness, we have always known that many children who are deaf-blind have a very sensitive sense of smell to compensate for their limited use of vision and hearing. Consequently, we have always said that the sense of smell plays a key role in this population for identifying people, places, objects and activities.

The following statements are heard frequently in this field: avoid wearing strong fragrances because they can elicit seizures in some children; use the sense of smell to provide additional information (olfactory cues) to the child about what is about to happen to the child, e.g., bringing a bar of soap close to the child's nose before taking a bath to tell him that soon he will be taking a bath; or to wear the same soft scent every time you work with a particular child so he can recognize who you are by this smell. All of this is very valuable information. The sense of smell is a strong sense for identification purposes and can have a strong impact in your brain because it is such an integral part of it (to the point that strong chemical smells can definitely elicit seizures).

But what about the role the sense of smell plays in relation with children's moods, levels of arousal, emotions, memories and physical reactions? Now we know that they are connected.

Many times we are with a child and we can't understand what is going on with him. He can't tell us in a formal way. Maybe he is fussy or crying or smiling and we don't know why. Why is he having these behaviors? Could it be about something he smells? We don't know. We definitely know we should be paying more attention to this environmental factor to see if and how this is affecting the child.

I still have some questions in relation to the impact of the sense of smell in children who are deaf-blind and whether we can use this sense for our advantage, e.g., the use of consistent olfactory cues that might provide information a child could use to better understand what is happening, or eliciting a specific response from a child using a specific scent.

Are children who are deaf-blind more impacted by the sense of smell than children who have normal vision or hearing?

Are children who are deaf-blind with neo-cortex lesions more strongly impacted by the sense of smell because they might depend more on the information processed by the limbic system?

Can we help a child become more alert or less overexcited using a particular scent?

Can we calm a child using oils that have a calming or soothing scent?

## CONCLUSIONS

Even though we don't know exactly how children who are deaf-blind are impacted through their sense of smell, we know this sense is very strong and basic. When interacting with a child who is deaf-blind we should be aware of the environmental odors that might be affecting the child's behavior. Ideally we should be pairing an odor with its source so the child can make the connection between what he is experiencing and its concrete referent.

As an educational specialist in the area of deaf-blindness, it would be interesting to work with a team that includes a neuroscientist and an aroma-therapist to find ways to use the sense of smell to the benefit of children who are deaf-blind.

The emotional connections and the memories attached to a smell seem to be very personal; it seems to be intrinsically enmeshed with the individual experience. I am certain that if another person had been walking with me that day several years ago at Macy's, he or she would not have noticed the doll's smell. And on perceiving the smell, he or she would not have thought of my doll Lucy or felt the same feelings I had with this

experience. But strong memories can be encoded and be accessible through the natural workings of the sense of smell. It may be possible to create these links to help open another avenue for communication with children who are deaf-blind.

## RELATED LINKS

<http://www.sfsu.edu/~cadbs>

(Utilizing the Sense of Smell in Children and Youth with Deaf-Blindness)

California Deaf-Blind Services Fact Sheet by David Brown, CDBS Education Specialist

See CDBS list of Fact Sheets with some topics available in Chinese, Laotian, Spanish, and Vietnamese:

<http://www.sfsu.edu/~cadbs/factst.html>; email [cadbs@pacbell.net](mailto:cadbs@pacbell.net) or call 800-822-7884

[http://www.driesen.com/the\\_limbic\\_system\\_-\\_2.htm](http://www.driesen.com/the_limbic_system_-_2.htm)

(The Limbic System) Driesen, Neuropsychology and Medical Psychology Resources

<http://web.sfn.org/content/Publications/BrainBriefings/smell.html>

(Smell and the Olfactory System) Society for Neuroscience - *Brain Briefings*, 1995.

<http://psych.athabascau.ca/html/Psych402/Biotutorials/18/intro.shtml>

(Limbic System) Athabasca University-Advance Biological Psychology Tutorials

<http://www.cf.ac.uk/biosi/staff/jacob/teaching/sensory/olfact1.html>

(Olfaction) Cardiff University-A Tutorial on the Sense of Smell

<http://www.serene-aromatherapy.de/aromaolfactory.html>

(The Olfactory Response) von Have, Serene Aromatherapy

<http://faculty.washington.edu/chudler/chems.html>

(Our Chemical Senses: Olfaction) Murray; Neuroscience for Kids Staff Writer

## Warning: BART Hits Texas!

By Gigi Newton, Texas Deafblind Project, Texas School for the Blind and Visually Impaired

*Abstract: Professionals in Texas are receiving training in Bonding and Relaxation Techniques (BART), massage for special needs infants and children.*

*Key Words: programming, infants, bonding, relaxation, massage*

BART has hit Texas thanks to Evelyn Guyer, a nurse educator, Certified Instructor Trainer, and author, and Tricia Lee, Vision Specialist for Region 9 Education Service Center, Wichita Falls, Texas. BART is not a new hybrid car, a computer virus, or even a summer hurricane. BART is Bonding And Relaxation Techniques training, a class for learning how to do massage for special needs children.

Evelyn Guyer, developer of the BART Program, has worked with families for over 38 years. She was the recipient of a federal deafblind grant to explore how massage may be used to help individuals with deafblindness. She is currently a Certified Instructor Trainer for the International Association of Infant Massage (IAIM).

Region 9 Education Service Center and Tricia Lee hosted 22 participants who attended the BART Certification Training in May. This training certifies them to teach BART techniques to parents. Additionally, six participants attended the BART Trainer Course that allows them to teach other professionals BART techniques. (This training of trainers was open only to people who have been BART certified for at least one year.)

## **HISTORY OF BART**

Evelyn Guyer developed BART in the late 1980s. It is based on infant massage techniques developed by Vimala Schneider McClure and specially designed to address the needs of infants, children and older individuals with special needs. These techniques were later applied to the special needs of dual-sensory impaired children, young adults and their parents through a grant funded by OSERS through New York State Education Department.

## **BENEFITS OF BART**

BART has many benefits for both the parent and the child. For parents it:

- Helps them learn to read the child's signals and cues;
- Helps the parent relax;
- Builds the parent's confidence;
- Creates a positive / constructive interaction time with the child; and
- Offers a fun activity to do with their child.

For the child, BART:

- Creates bonding / attachment between the child and parent
- Stimulates the respiratory system;
- Stimulates the circulatory system;
- Stimulates the gastrointestinal system;
- Speeds myelination of the brain/nervous system in infants;
- Aids in body organization for all children;
- Provides psychological benefits (safety, learning touch is safe);
- Provides relaxation for the child; and
- Enhances interactions and communication between the child and parent.

## **WHO CAN DO BART?**

Since bonding is an outcome of this activity, only a parent or a primary caregiver should do BART with a child. BART should not be an activity for the child with a teacher. Parents should work one at a time with a child although receiving a massage from both parents is a wonderful idea. If the child or individual is older and living in a group home or other setting one caregiver should be trained to provide this activity.

## WHAT DO YOU LEARN AT BART TRAINING?

During BART training parents and caregivers learn specific techniques that can be used at home. This includes among others, massage techniques to increase body awareness and muscle tone, to improve upper respiratory function, decrease tactile defensiveness, improve coordination, and improve elimination problems (constipation).

There are specific environmental considerations when using BART with an individual. At the BART training you learn about things such as:

- How to maintain the appropriate room temperature,
- Lighting considerations,
- The importance of a comfortable mat,
- The appropriate massage oils to use,
- Adding music to the activity,
- Appropriate child's clothing for a massage, and
- How to maintain the child's privacy and dignity.

Participants in the training also learn how important timing is in making the experience an enjoyable and positive one for both the parent and the child.

## WANT MORE INFORMATION?

During the 2005-2006 school year, we hope to see many BART training activities taking place all around Texas. If you would like more information about BART or about locating a BART training in your area, contact your vision consultants at your education service centers or Cyral Miller, Director of Texas School for the Blind, Outreach Department, by phone (512-206-9242) or email <[cyralmiller@tsbvi.edu](mailto:cyralmiller@tsbvi.edu)>

### An Amazing Movement

by Phil Hatlen, Superintendent, Texas School for the Blind and Visually Impaired

*Abstract: an article with a personal story that illustrates how the Expanded Core Curriculum affords equality of opportunity for student who is blind or visually impaired.*

*Key Words: Expanded Core Curriculum, ECC, Phil Hatlen, TSBVI*

In the United States, Women's Suffrage is over 100 years old. Amazing things have happened in the arena of equality for women, but if Harriet Beecher Stowe were alive, she would tell you that true equality has yet to be achieved. Over 50 years ago civil rights for minorities became a high priority in my country. And many aspects of the lives of African-Americans and Hispanics have improved. Yet, Martin Luther King Jr. would tell you that equality for all races is still a dream. About 15 years ago our profession was introduced to a new term: Expanded Core Curriculum.

These other movements were originated to provide equality for women and African-Americans. Is there a parallel with the ECC? I've never thought before about how learning the skills offered by the ECC brings blind persons closer to equality with sighted persons. If we professionals are committed to equal opportunities for blind and visually impaired persons, how could we think of the curriculum within the ECC as optional? The Expanded Core Curriculum provides opportunities for equality for the blind and visually impaired; to NOT teach it is to deny this basic human right.

It has been endorsed and supported by most major agencies and organizations of and for the blind, it is known and adopted throughout the world, and it is included in most teacher preparation programs. But even Phil Hatlen will tell you that the majority of blind and visually impaired children in this world are not receiving much of the ECC.

What's the moral of this story? Dramatic change, in attitudes and in service delivery, takes time. As I was writing these words, ready to guilt-trip all of you because you believe in the ECC but are not teaching it, a friend of mine reminded me of the above timetable. She said that to deliver the ECC to all students who need it will require a major paradigm shift, one that doesn't happen instantly or easily. So, my friend said, why don't you write about the amazing strides that have been made toward complete delivery of the ECC in a short 15 years? Now, I'm an old curmudgeon, been around a long time, and find it always easier to be critical than complimentary. Then the ECC cheerleaders at TSBVI marched into my office, pom-poms and all, and led a hearty cheer for the good old ECC. Fine, fine, I mumbled, I'll write something uplifting and positive about this topic of which I'm so passionate!

This will be the first of several installments in *See/Hear* representing my current thinking about the ECC. Each will contain one story of my history that will explain why I have so much passion and commitment to this topic.

I once knew a woman named Mamie Clemmons. She was on the residential staff of the California School for the Blind in Berkeley. Around 1968 I lost track of her, later to discover that she had bought a large house in the foothills of North Berkeley.

Mamie moved into this house along with six recent graduates of the California School for the Blind. She knew all the young people living in this house from their days at CSB. She knew that when they graduated from CSB, they would not be ready to enter into the social, educational, and occupational mainstream of their communities. She knew what they knew—most were very bright, capable academic students. She knew what they didn't know—how to live effectively, happily, and productively in the community.

So Mamie started a halfway house for blind young people who needed some maturing and a lot more independence before they ventured into the community by themselves. She didn't know much about vocational training, instruction in independent living skills, orientation and mobility, etc. But Mamie knew a lot about what blind students didn't know because they could not learn visually and casually.

In the middle of a huge room on a table was a large bowl of fruit—bananas, oranges, apples, etc. Mamie pointed to the bowl and said, "When these young people were at CSB, they ate when they were told to eat, they had almost no knowledge of snacks. I put out this bowl of fruit and told them to help themselves any time. They were shocked—they didn't have to ask permission, it could be any time of the day." Mamie went on to say that if these young people had grown up in their family homes, this wouldn't have come as such a surprise.

I connected myself to Mamie, those young people, and that house for more than a year. And I slowly came to realize what had been so obvious to Mamie. We were graduating students from our high schools who may have been excellent academic students but were ill prepared for life.

We should be proud, and stand tall, because the ECC has advanced so much in a short period of time. Stowe never lived to see the equality of women. MLK Jr. never lived to see civil rights provide equality to all cultural and ethnically different people. But think about how their work moved us closer to equality among all people. Now, I would never be so presumptuous as to put myself in the same category of Harriet Beecher Stowe or Martin Luther King, Jr. But, in a very similar manner, the ECC is gaining momentum just as these other monumental changes have done.

As with Stowe and King, I will not live to see the day that the ECC becomes a regular part of the curriculum for all blind and visually impaired students. All I can do is push it along, a step at a time, and know that future generations like you will pick up the passion, the commitment, the understanding that the ECC must be a part of the daily learning activities of children.

## Legislative Matters

By Barbara J. Madrigal, Assistant Commissioner, Division for Blind Services

*Abstract: this article provides a review of the 79<sup>th</sup> legislative session, including appropriations for programs and services, rates for medical services, and employee benefits.*

*Key Words: DBS, Texas Legislature, blindness, funding, appropriations*

As I write this, the 79<sup>th</sup> Texas Legislature is getting ready to reconvene in special session to tackle the school finance issue again. While it's true the Governor can add topics to the agenda, at this time there's no reason to believe lawmakers will take up anything directly related to the Division for Blind Services' (DBS) funding or programs.

So, DBS will continue to analyze and implement legislation from the regular session that impacts our division. In this article, I'll hit some of the highlights pertinent to our budget, services, staff and consumers.

First, however, I would like to express my appreciation for all DBS staff members for their amazing dedication and hard work to get us through another legislative session. The fast pace of the session and constant need to respond rapidly and accurately is demanding and stressful. While we rely heavily on a few staff as legislative "first responders," everybody else pitches in to keep our day-to-day operations running smoothly. We have a proud tradition of teamwork at DBS, and this is yet another fine example.

Now we move on to legislative matters. I'm including a few items of immediate interest to consumers and employees. If you're interested in reading about these items in more detail or learning about other legislative actions, I've added some useful Internet links at the end of the article.

## **APPROPRIATIONS FOR PROGRAMS AND SERVICES**

- As you may recall, DARS was required to submit a Legislative Appropriations Request reflecting a five percent reduction in state funding for programs that included DBS' Business Enterprises of Texas (BET) and Blind Children's Vocational Discovery and Development Program (BCVDD). The appropriations conference committee restored those funds.
- The legislature also granted DARS capital authority to create a new, web-based consumer case management system that meets the business requirements of the Vocational Rehabilitation programs administered by DBS and the Division of Rehabilitation Services (DRS).

## **RATES FOR MEDICAL SERVICES**

- When DBS and DRS merged into DARS, each had a different methodology for setting rates for medical services. With the passage of HB 1912, the legislature authorized DARS to develop a single, cost-based rate setting process. We will provide more information for medical providers as we move forward with this mandate.

## **STATE EMPLOYEE SALARIES & BENEFITS**

- All state employees who are not part of the higher education system will get a pay hike. The majority (including DBS employees) will get a four percent salary increase (minimum \$100 per month) effective Sept. 1, 2005 followed by a three percent increase (\$50 minimum) effective on the same date next year. (Note: Several state employee groups (child protective services, public safety officers and others) are getting raises on a different pay structure.)
- Legislators also approved increases in longevity and hazardous duty pay for state employees (including higher ed). Effective September 1, 2005, longevity pay increases to \$20 per month for every two years' service. Hazardous duty pay goes up to \$10 monthly. The legislature did not provide additional funds for the increases, leaving it up to agencies to finance them.
- Employee and retiree health benefits will remain basically the same. This is a relief considering the costly changes legislators enacted in the previous section.

For more information on these and other topics, I suggest these websites:

Employee Retirement System of Texas: <<http://www.ers.state.tx.us>>

Texas Public Employees Association: <<http://www.tpea.org>>

Texas Legislature Online: <<http://www.capitol.state.tx.us>>

In closing, I would like to thank those of you who support and advocate for DBS. You are strong and devoted allies and we recognize your important role in our quest to provide effective and meaningful programs and services for Texans who are blind!

Thanks for your time and interest. As always, if you have questions or concerns about this article or other DBS issues, feel free to contact me: 512-377-0603 or <[barbara.madrigan@dars.state.tx.us](mailto:barbara.madrigan@dars.state.tx.us)>.

Happy Summer!

## Communication Matrix Assessment Tool Available Online

From <[www.communicationmatrix.org](http://www.communicationmatrix.org)>

*Abstract: This website announces the availability of the Communication Matrix online, an assessment tool designed especially for parents and offered as a free service to parents.*

*Key Words: Communication Matrix, communication skills, Dr. Charity Rowland, speech-language, sensory impairments, cognitive impairments*

**What is It:** The Communication Matrix is an assessment tool designed to pinpoint exactly how a child is currently communicating and to provide a framework for determining logical communication goals. It was first published in 1990 and was revised in 1996 by Dr. Charity Rowland of Oregon Health & Science University. It was designed primarily for speech-language pathologists and educators to use to document the communication skills of children who have severe or multiple disabilities, including children with sensory, motor and cognitive impairments. The original version for professionals is still available for purchase. It uses a concise format that is designed for rapid administration by persons familiar with the assessment.

This online version was designed especially for parents. It is also available for purchase in a printed version. The parent version is designed to be “user friendly”. The results are summarized on a one-page Profile. The Profile is a matrix that shows at a glance what level of communication behaviors your child is using and what kinds of messages he or she expresses. The Profile is exactly the same as the profile generated by the professional version of the Matrix. That means that parents and professionals can both use the same form to show each other how the child is communicating at home and at school.

**Target Population:** The Communication Matrix is appropriate for individuals of all ages who are at the earliest stages of communication. In the typically developing child the range of communication skills covered by the Matrix would occur between 0 and 24 months of age. The Matrix accommodates any type of communicative behavior, including “augmentative and alternative” (AAC) forms of communication and pre-symbolic communication. It is appropriate for individuals who experience any type or degree of disability, including severe and multiple disabilities. The Communication Matrix is NOT suitable for individuals who already use some form of language meaningfully and fluently.

Throughout the Matrix material, the person being assessed is referred to as “your child”. Please note that the Matrix is equally applicable to adults who are functioning at the earliest levels of communication. It may also be useful for assessing young children without disabilities who are in the early stages of communicative development.

**Why an Online Version:** The online version of the parent matrix has been developed for several reasons:

- It’s easy to use. You are guided step-by-step through the process of entering the information and you do not have to leaf through sections that are not relevant to your child.
- It generates clear results. When you use the online version, the results are automatically entered into the Profile and you may print out clean copies for yourself and your child’s educational team. A summary of communication behaviors and messages used by your child is also generated.

It’s free. This is a free service that is available to anyone who wants to use it.

Your Contribution: When you use this free service, we ask you to provide some very basic information about the individual that you are assessing (gender, age, ethnic background, country of residence, disability and specific impairments) and your relationship to that person. We DO NOT request any identifying information and we have no way of tracking who has used this service. When you complete the Matrix online, the information you provide will be stored. This information will provide valuable data about the communication skills demonstrated by individuals with various disabilities. This information may be summarized in scientific reports, professional presentations, articles in professional journals and book chapters.

## Offering Information and a Crucial Link

Announcement from the Cornelia de Lange Syndrome Foundation

*Abstract: announcement that comprehensive information packet and newsletter about CdLS is available and information on how to access information.*

*Key Words: Cornelia de Lange Syndrome, CdLS, American Legion Child Welfare Foundation, blind*

Doctors, therapists, and educators shape our lives in countless ways. At the CdLS Foundation we continue to reach out to professionals providing them with vital information about CdLS. We also provide a much-needed link between families and knowledgeable professionals.

Thanks to the generosity of the American Legion Child Welfare Foundation we are able to mail a comprehensive information packet about CdLS as well as a year of issues of our newsletter "Reaching Out" to any interested professional. Many professionals who initially contact the Foundation to learn more about the syndrome become valuable resources for the families in their area. With your help we would like to continue to educate professionals and build our nationwide network of support.

If you know of a caring professional who would benefit from more information about CdLS or if you would like to recommend a professional that you work with as a resource for others, please reply to this email with the following information: name of professional, her or his area of expertise, address, email, phone number, her or his preference for contact (email, phone, or mail), and your name. (Optional: number and names of people with CdLS this professional has served.)

If you are a doctor, therapist, or educator who does not currently receive Reaching Out, please reply to this email with the following information: your name, area of expertise, address, email, phone number, preference for contact (email, phone, or mail). (Optional: number and names of people with CdLS you have served.)

Thank you for helping us find support for all who request it.

Kalia Kellogg, Director of Communications  
Cornelia de Lange Syndrome Foundation  
302 West Main Street, #100  
Avon, CT 06001  
P: (860) 676-8166  
F: (860) 676-8337

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

## New from Sprint Relay: Online Services!

From the <[sprintrelayonline.com](http://sprintrelayonline.com)> website

*Abstract: Sprint Relay services now include capacity to make a call from any internet connection. The Sprint website provides information about this service.*

*Key Words: Sprint Relay, accessibility, deafblind, assisted communication devices*

Assisted communication devices like TTY/TDD's keep everyone talking – but they don't fit in your pocket. Don't let location or equipment accessibility limit your ability to make Sprint Relay calls. With Sprint Relay online, place calls from any internet connection. There's no need for traditional teletype (TTY) equipment. The Web interface can handle the conversation. Sprint Relay Online is a free service that combines traditional relay service with the ease of the internet.

Communicate on the go. Point your browser to <[www.sprintrelayonline.com](http://www.sprintrelayonline.com)> and begin typing your conversation to a Sprint Relay operator, who will then read aloud the typed conversation to the person listening on a standard telephone or wireless handset. The operator will then type that person's words and read them back to you.

Make appointments from an internet cafe. Catch up with friends from the library's computer area. Call home from the school's computer lab. There's no charge – long-distance or local – with Sprint Relay Online.

### **Book Review: *Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew*, edited by Stanley D. Klein, Ph.D., and John D. Kemp**

Excerpted from <<http://www.disabilitiesbooks.com/topics.htm>>

*Abstract: this article reviews a collection of essays written by successful adult role models who share the experience of growing up with a disability.*

*Key Words: disability, blindness, parenting, role models, Stanley D. Klein, John D. Kemp*

Most parents of children with disabilities lack personal experience with adults with disabilities. Hearing from people who have lived the disability experience can provide all parents with essential information about the possibilities for their children.

*Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew* (McGraw-Hill, 2004), edited by Stanley D. Klein, Ph.D., and John D. Kemp, who also wrote the book's Afterword, includes forty inspiring and realistic essays written by successful adult role models who share what it is like to have grown up with a disability.... In preparing their essays, the authors were asked to write about something they wished their own parents had read or been told while they were growing up....

Brimming with a wealth of life-affirming lessons, *Reflections from a Different Journey* offers many specific suggestions for parents as well as older children with disabilities, family members, and the education and health care professionals who serve them.

Stanley D. Klein, Ph.D., a clinical psychologist and frequent speaker to parents and health care and education professionals from Brookline, Massachusetts, has worked with children with disabilities and their parents for fifty years and has received numerous national awards for his work. A cofounder and former editor-in-chief of *Exceptional Parent* magazine, Dr. Klein has coedited *The Disabled Child* and *the Family* (*Exceptional*

Parent Press, 1985), *It Isn't Fair: Siblings of Children with Disabilities* (Greenwood Publishing Group, 1993), *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities* (Kensington Books, 2001) and *From There to Here: Stories of Adjustment to Spinal Cord Injury* (No Limits Communications, 2004).

John D. Kemp is a successful Washington, DC attorney and lifelong advocate for the rights of people with disabilities. With the Law Firm of Powers, Pyles, Sutter & Verville, P.C., Mr. Kemp represents the legal and professional interests of a wide range of for-profit companies and not-for-profit organizations. He is a frequently sought-after speaker, giving up to fifty keynote presentations each year. Mr. Kemp has been recognized for his work on behalf of people with disabilities, including service as the 1960 National Easter Seals Poster Child, 1991 membership in the Horatio Alger Award of Distinguished Americans, the Freedom of the Human Spirit Award from the International Center for the Disabled and an Honorary Doctorate of Laws and the Distinguished Alumni Fellow Award from his alma mater, Washburn University Law School.

Reflections is available at <[www.DisABILITIESBOOKS.com](http://www.DisABILITIESBOOKS.com)> and other bookstores. For a list of other topics that Dr. Klein often speaks about, please go to <<http://www.disabilitiesbooks.com/topics.htm>>.

## Labels for Literacy Program

Original article by Ann Foxworth, Braille Consultant, Division for Blind Services;  
updated by Beth Dennis, BCP/Transition Consultant, Division for Blind Services

*Abstract: This article describes the Labels for Literacy Program, a free Braille labeling service.*

*Key Words: Braille, Labels for Literacy Program, labeling system, household organization.*

Have you or your consumers ever had the experience of opening the wrong can or even the wrong medication container? Imagine preparing to sit down to a hearty bowl of soup, only to open it and discover that you are about to feast upon a hot, steaming bowl of fruit cocktail!

Labels for Literacy is a program designed to place more Braille on mainstream products in order to increase the usage and understanding of Braille and to bring equality of access to brand and product information for the blind and visually impaired consumers. According to the Labels for Literacy website, the program's mission includes three important goals.

1. Develop a comprehensive Braille labeling system that will provide the opportunity for all persons, blind and sighted, equal access to label information.
2. Proliferate the production of Braille on mainstream products such as consumer goods labels to promote the use and understanding of Braille, therefore increasing Braille literacy.
3. Allow consumer packaged goods organizations the opportunity to advertise and communicate their brand's identity on an equal basis to all consumers.

The Labels for Literacy program will accomplish this by producing sheets of self-stick labels that identify common brands and products in large print and in Braille. These labels will then be distributed at no cost to blind and visually impaired individuals nationwide.

Vocational Rehabilitation Teachers with the Division for Blind Services have received these packets to distribute to consumers. Consumers and parents may also obtain the packets by contacting Labels for Literacy directly at: The Labels for Literacy Program; Tel: (866) 32-LABEL; <[info@labelsforliteracy.com](mailto:info@labelsforliteracy.com)>.

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# CLASSIFIED

Mail or e-mail your new classified to Carolyn Perkins:

TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or <carolynperkins@tsbvi.edu>.

An up-to-date Statewide Staff Development Calendar is posted on TSBVI's website at <www.tsbvi.edu>

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## The Deaf-Blind Multihandicapped Association of Texas (DBMAT)



### 33rd Annual Statewide Family Conference

#### “Hat’s Off to the Future”

A Fun-Filled Learning Weekend for the Entire Family

**October 7-9, 2005**

Camp John Marc, near Meridian, Texas

For more information, contact:

Cyndi Hunley, Conference Registrar

23202 Bright Star; Spring, TX 77373

281-836-9005

chunley@aol.com

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## CAMP CONNECT

Forth Annual Retreat for  
Central Texas Families of Children with  
Combined Hearing and Vision Loss and  
Deafblindness

Peaceable Kingdom Retreat - near Temple, TX

Sponsored by DARS - Division for Blind Services  
Region 12 Education Service Center,  
Region 13 Education Service Center  
Texas Deafblind Outreach

### Coming this fall

If you are interested in learning more about this  
event call Tina Herzberg at Region 12 ESC in Waco  
254-666-0707.

This retreat is provided free of charge to families,  
including lunch and dinner. Travel assistance is avail-  
able for families to cover the cost of gas. For families  
who are unable to bring their children due to age or  
medical considerations, reimbursement to help cover  
the cost of child care for the child at home is also avail-  
able. Overnight accommodations may also be pro-  
vided free of charge if necessary.

## 7th Annual Virginia Murray Sowell Center Distinguished Lecturer Series

### *Assistive Technology for Children with Visual Impairments*

Featuring training sessions, product  
demonstrations, lunch , and door prizes

**October 8, 2005**

### **Texas Tech University**

College of Education, Room 001  
Lubbock, Texas

Contact: Anita Page  
(806) 742-1997, ext. 22  
for more information as it develops  
or check the website at  
<[www.educ.ttu.edu/sowell](http://www.educ.ttu.edu/sowell)>

## Sports Extravaganza

**October 21-22, 2005**

**Nimitz High School; 100 W. Oakdale; Irving, TX**

The 7th annual Sports Extravaganza for Students with Visual Impairments will be held at Nimitz High School in Irving, Texas on October 21-22, 2005. Students with visual impairments ages 6 through 22 will compete in track and field events, goalball and beep baseball events, and recreational skills of archery and golf drive for distance on Saturday. In addition, there will be activities for students ages 0-5 in the Low Organized Activities area, and events for students with visual and multiple impairments ages 6-22. The Friday night Goalball Tournament will showcase teams from Texas, New Mexico and Colorado. Region 10 Education Service Center along with Lions Club International is proud to sponsor this event.

For more information please contact Christy Householter at 972-348-1634,  
or <[househol@esc10.ednet10.net](mailto:househol@esc10.ednet10.net)>.

Packets or brochures are available on request or on our website in August, 2005 at:  
<<http://www2.ednet10.net/ssvi/Vision.htm>>

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## SWOMA 2005

Southwest Orientation and Mobility Association

**November 18-19, 2005**

**San Antonio, Texas**

For information, contact:

Emily Leeper

<eleep006@neisd.net>

210-637-4963

## MARK YOUR CALENDARS!

Texas Deafblind Outreach is planning these two training events:

### Getting a Life:

### Transition Planning for Students with Deafblindness

**November 12 & 13**

**Austin, Texas**

For More information, look for the flyer later this fall, or contact:

David Wiley: (512)206-9219

<davidwiley@tsbvi.edu>

or

Beth Bible: (512)206-9103

<bethbible@tsbvi.edu>

### Usher Weekend

for students with Usher Syndrome and their families

**January 14-16, 2006**

Look for more information in the fall edition of *See/Hear*.

## Helen Keller National Center 2005 Seminars

Leona & Harry B. Helmsley Conference Center  
141 Middle Neck Road  
Sands Point, New York

**Interpreting Techniques for the Deaf-Blind Population**  
August 20-23, 2005

**Enhancing Services for Older Adults with Vision and Hearing Loss**  
September 12-16, 2005

**Transformation: Imagine the Possibilities: Person-Centered Approach to Habilitation**  
October 17-21, 2005

**Expanding the Arena: *The Magic of Technology***  
November 14-18, 2005

Contact: (516) 944-8900

<hkncinfo@hknc.org>

<www.hknc.org>

## Getting In Touch With Literacy 7th Biennial Conference: *Living Literacy*

**December 1-4, 2005**

Denver Marriott City Center, 1701 California St.  
Denver, Colorado

A national conference focusing on the literacy needs of individuals with visual impairments.

For more information contact:

Dr. Kay Ferrell

NCLID, McKee Hall Campus Box 146

University of Northern Colorado,

Greeley, Co 80639

<kay.ferrell@unco.edu>

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## Short Classes at TSBVI

Do you have an academic student or child who might benefit from a week of intensive training in one or two vision-specific learning domains? Would you like your child or student to participate in a long weekend class focusing on issues related to vision loss? If so, you may want to read this.

### ABOUT SHORT CLASSES

TSBVI Short-Term Classes serve students who are functioning at or close to grade level. Students come from across Texas to participate in our one-week or long-weekend small-group classes. These are students whose basic needs are well met in the local school district, but who may need a short, intensive training boost in one or two disability-specific areas (e.g., O&M, independent living, technology, aspects of the braille code, math concepts or adaptations). While at TSBVI, students also have experiences related to social skill development, interactions with other visually impaired students and professionals, and independent living.

Students must be referred for a Short Class by their local school district. Students are requested to bring their week's school assignments (homework) with them. This serves two purposes: (1) the opportunity to teach new skills within the context of what students are learning at home, and (2) helping students keep up with their assignments while they are away. Before students come to a Short Class, their local VI teacher and TSBVI teachers discuss the student's current level of functioning in the skill areas selected for instruction, to maximize effective instruction as soon as the students arrive.

### SHORT CLASSES FOR THE 2005–2006 SCHOOL YEAR

Below is a listing of Short-Term Classes for next year. If you have an upcoming ARD, this could be a time to talk about a possible referral. Please call TSBVI principal, Lauren Newton, if you have any questions about the program or if you want to make a referral to one or more classes.

#### Fall Semester 2005

September 11 - 16 Technology Week #1  
(secondary)  
September 25 - 30 Middle School IEP #1  
Oct 16 - 21 High School IEP #1  
\*October 27- 30 Middle School Independence  
Weekend  
November 6 - 11 Elementary:  
• Elementary IEP #1  
• Elementary Math Tools &  
Concepts  
Nov 27 - Dec 2 Math Tools and Concepts  
(secondary)  
December 8 - 11 "Getting There" Weekend  
(grades 9-12)

\* Long-Weekend Program

#### Spring Semester 2006

January 8 - 13 High School IEP #2  
\*January 26 - 29 Fitness at Home & in the  
Community (secondary)  
February 5 - 10 Middle School IEP #1  
\*Feb 16 - 19 Low Vision Weekend  
(secondary)  
Feb 26- March 3 Technology Week #2  
(secondary)  
\*March 23- 26 Elementary Independence  
Weekend  
\*Mar 30 - Apr 2 High School Independence  
Weekend  
April 23 - 28 Elementary  
• Elementary IEP #1  
• Elementary Technology

\* Long-Weekend Program

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# SEE/HEAR

Published quarterly: February, May, August, and November  
Available in Spanish and English on TSBVI's website at <www.tsbvi.edu>  
Contributions to the newsletter can be mailed or emailed to section editors at:

TSBVI Outreach  
1100 West 45th Street  
Austin, Texas 78756

**If you no longer wish to receive this newsletter, please call Beth Bible at (512) 206-9103 or email <bethbible@tsbvi.edu>.**

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December 1st for the Winter edition

March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

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The audio version of SEE/HEAR is provided by  
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This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education. The Outreach Programs are funded in part by IDEA-B Formula, and IDEA-D Deaf-Blind Federal grants. Federal funds are administered through the Texas Education Agency, Division of Special Education, to the Texas School for the Blind and Visually Impaired. Texas School for the Blind and Visually Impaired does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

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