

SEE/HEAR

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

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Section Editor's Introduction: The Family Section in this edition continues a series of family-focused articles dealing with the subject of the expanded core curriculum for students with visual impairments, including those with deafblindness and multiple disabilities. The last edition addressed recreation and leisure skills. This issue focuses on career education. We asked Gene Brooks and Brandy Wojcik to share with our readers what they thought was critical to helping a child with visual impairments or deafblindness to succeed as an adult and to find their career path. We appreciate their insights and reflections. Career education begins at birth and is relevant to all children, including those who may not follow traditional work paths. For some individuals, like Brandy and Gene, career education means preparing for the world of work. For others, like Corry, Melanie and Keith's children, career education expands its focus to preparing for a self-determined life-style in adult life.

Preparing for the Workplace Pays Off for Children with Disabilities

Reprinted with permission from the Summer, 2001, issue of the *Pacesetter*, a publication of the Pacer Center, Inc., Minneapolis, Minnesota.

Abstract: This article lists eleven practical and effective strategies parents can do to help their child develop the skills they will need to be successful in the world of work. Although the article was written for children with a range of disabilities, the strategies listed can be used for any child.

Key words: blind, deafblind, parents, practical suggestions, career education, expanded core curriculum

The article is an excerpt from *When I Grow Up, I Am Going to Work*, a PACER Center Project Youth book for children; Diane Hovey, project coordinator, and Caryn Pernu, editor. The booklet may be purchased from the PACER Center at \$8 per copy (\$6 for 10 or more). For more information contact the PACER Center at 8161 Normandale Blvd., Bloomington, MN 55437-1044; (952) 838-9000 voice; (952) 838-0190 TTY; (952) 838-0199 fax; <www.PACER.org>. All rights reserved.

Parents may feel mixed emotions about the child with disabilities growing up and going to work. They may share the child's excitement about future possibilities, but they may also worry about the child's vulnerability of possible failure at a job. Helping children develop job skills is one of the biggest gifts parents can give because it enriches children's sense of self and builds potential for their future.

How can parents assist their young children to become ready for work? Here are some helpful ideas:

1. Teach social skills

More people lose jobs because of personality conflicts and the inability to work with other people than for any other reason. Providing children with opportunities for social interaction is very important. Preschool groups, religious groups, scouting groups, and community recreation programs are examples of good places to learn social skills.

2. Give children specific chores

Parents can help their children choose chores they can do with little assistance. Even children who have physical limitations that require assistance can still be given chores. For instance, the tray on a wheelchair can be used to deliver dishes to the table or folded laundry to the correct room. Occupational therapists can provide assistance if adaptations are needed to accomplish the chore. Not only will children be proud of their work, but they will also be contributing to the needs of the family.

3. Provide daily opportunities for children to make choices

Parents can start by asking children to make simple and familiar choices such as what to wear or what to eat. They must be sure the choices are ones their children are able to make and be careful to avoid offering options that are not possibilities. At first, parents can limit options by offering children a choice between two items. Later, the number of options can increase as children develop skills.

4. Teach communications skills

Children need to learn communications skills, as well as how to express feelings in a socially acceptable way, take criticism without becoming outwardly upset or angry, cooperate with others, ask for help when needed, and ask for more work once initial tasks are complete. Role playing can be an effective tool in learning communication skills.

5. Help children identify interests

Parents can provide opportunities for a variety of activities so children can explore different interests. Hobbies are an enjoyable way to learn skills and can lead to job opportunities. Children who like sports, for example, may eventually work in a sports store or at a camp.

6. Keep a notebook

Parents can keep a list of their children's interests and the places where they seem most comfortable. Parents can also note their children's skills and strengths and what motivates them to follow through on their tasks. In this way, parents learn more about their children and also better see the progress their children make.

7. Help children to be punctual

Parents can teach their children to set an alarm clock and wake up on time for school. Children can learn to prepare for the next day by laying out their clothes the night before. Parents can assist their children in calling if they cannot attend an activity.

8. Allow children to experience natural consequences

Parents often want to shelter their children from any pain or sadness, but this is a natural part of life for children with disabilities as well. When children make a choice and it turns out to be a bad decision, parents can provide the opportunity for their children to learn about natural consequences. Everyone learns from mistakes. Parents can be there to support their children but let them make mistakes and learn from them.

9. Talk to children about jobs

Parents can talk to their children about different jobs. They can point out what people are doing in their jobs and ask their children's opinions about the tasks. Children can visit their parents' workplaces and help.

10. Encourage volunteering

Volunteering can teach children much about what is expected at work without putting too much pressure on them. Volunteer experiences provide opportunities to learn job skills, meet new people, learn to communicate with people who are not used to being with people with disabilities, and learn to do a task in a certain time period and do it well. It is a great opportunity for career exploration.

11. Promote self-advocacy

By providing choice and opportunity and teaching decision-making skills, parents are helping their children build

a foundation for self-advocacy. Parents can teach their children about their disabilities and how to communicate their needs. They can provide opportunities for their children to express their thoughts and opinions and exercise control over their environment. Later in the workplace, these skills will assist young adults in asking for what they need, especially for any special equipment or necessary changes to the workplace that will help them better do their jobs.

Starting early in preparing children for work will ensure they have better opportunities to be successful in their employment. Most importantly, parents can expect that their children will grow up to work, and they can help their children build dreams.

Do You Believe in Your Child?

By Gene I. Brooks, Ph. D. , Governing Board Member for TSBVI, Austin, TX

Abstract: The author of this article shares his personal story of growing up as a person with visual impairments in the days of segregation and the steps he took to develop effective job skills that have helped him become successful.

Key words: blind, deafblind, personal story, career education, expanded core curriculum

When I was first approached about writing this article, my immediate reaction was that I don't have any helpful information to share with parents of blind children. However, after giving the article some thought, I realized that just maybe my story might help give hope to someone. After all, had it not been for my uncle and a handful of very special teachers along the way, I wouldn't be who and where I am today. These were special people because they believed in me, and they verbally let me know that they believed in me. But unfortunately, there are many children currently in special education who never hear encouraging words such as: you're going to grow up and do wonderful things or you're going to be a doctor when you grow up. Therefore, this article is about how I came to believe in myself and to say to parents: Let your children hear you say to them, "I believe in you!" But first some background.

KINGSVILLE, TEXAS AND THE EARLY YEARS

Much like my grandfather before him, my father found himself working for the railroad in Kingsville, married and with five children. My twin sister and I are the youngest children. We were born on June 14, 1951. We grew up with lots of love from a large extended family and a community that cared. During my sister's and my delivery everything appeared to be normal with the exception of my starting to be born feet first. Over the next several years, my mother watched me to make sure that I hit all of the developmental milestones, not knowing if there had been some type of birth defect. At the age of three, my mother and aunt noticed that my left eye was pulling, and decided to take me to see an optometrist where the diagnosis of lazy eye was made (strabismus). The prescription for lazy eye at that time was for me to receive a pair of glasses and to wear a patch over my stronger eye, trying to make the weaker eye stronger. In short, over the next two years, I received two unsuccessful operations attempting to correct the problem.

SEPARATE BUT NOT EQUAL

In 1955, our mother enrolled my sister and me in a kindergarten class at a Catholic school even though our segregated school was doing a good job of educating black children. Our mother felt that we would receive a better education from the Catholic school in spite of the fact that all of our black teachers in our segregated school were hand picked from black teacher colleges and were thought to be some of the best and the brightest. While we were allowed to attend parochial school with Mexican-Americans in the early grades, we were not allowed to attend school with Whites at all until the late 1950s, and even at that time we were not educated together with Whites until the seventh grade.

My first school experience proved to be traumatic for me. Early on, I remember telling my mother that I didn't like going to the Catholic school because the nuns were mean. I felt they were mean because they used a ruler to hit me on the back of the hand when I made any type of mistake. And because I made lots of mistakes, my little knuckles stayed sore. After listening to me complain for months, my mother decided to withdraw both my sister and me and put us in our neighborhood school. Over the next three years I continued to have problems learning. After being retained in the first and the second grade, it was decided that I was mentally retarded and needed to be sent to a separate school that served children with mental retardation. After being there for about six months, I remember my teacher sending a note home with me asking my mother for a parent conference. It was at that time my teacher told my mother that she didn't think I was mentally retarded but that I might have a visual problem. So over the next several years my mother took me to Houston to undergo numerous medical exams. In 1960 I received the diagnosis of retinitis pigmentosa (RP), and it was at that time my mother decided to move us to Houston so I could receive a better education.

In 1961 we made the move to Houston, I started a sight savings class, and I loved all of it. For the first time I was learning. I was learning because the special materials that were used allowed me to see what was on the blackboard, read from large print books, and for the first time to interact with other children who had visual impairments like myself. I remained in the Houston school system until the fall of 1966 and at that time my mother enrolled me in the Texas School for the Blind. I was first scheduled to attend the school in the fall of 1965, but my start date had to be pushed back one year due to desegregation. At that time, all blind black students attended DB&O, which stood for Texas Deaf, Blind, and Orphan School, and all white blind students attended the School for the Blind.

In the fall of 1966, I arrived on the campus of the School for the Blind and I thought I was in heaven. Again, I saw other children who had visual impairments like me and, for the first time, I had the opportunity to participate in competitive sports and to date. However, my transition from Houston to the School for the Blind wasn't all good. Like the rest of society, the school was going through desegregation and there were some who didn't want us there and they tried to make our lives difficult. But as for me, I didn't really let it bother me that much because I thought I was in heaven, being surrounded by so many beautiful blind people.

When I first arrived at the School for the Blind I was placed back into the first grade. It's important to point out here that in 1966 - 1967 I was fourteen years of age and in a classroom with children who were only six years of age. Some of those students only came up to my knees when they stood up. After the school saw I could do the first grade work, I was moved into the third grade and I stayed there until I, along with many other black students, was placed back into a nonacademic track. I stayed there until about 1969. In the 1969 - 1970 school year, several teachers began to question why so many black students had been placed into the nonacademic track. I remember overhearing a parent talking with one of the concerned teachers telling her to go to the administration and demand that her child be placed back into the regular academic track. After hearing that conversation I decided to go to that same teacher and tell her that I wanted to be placed back into the regular track and that I wanted to graduate with a regular diploma. She suggested that I call my mother and ask her to make an appointment with the superintendent so she could discuss placing me back on track. A week later, I saw the superintendent in the hallway and I told him that my mother was concerned about me being in the nonacademic track and would therefore be calling him about placing me back into the regular academic track. Well, two weeks later, I was back in the regular track and very happy. What was interesting about me being moved back was that I never told my mother anything about the earlier conversation I had with the teacher or the superintendent, and therefore, my mother was never apprised of what was going on. But it worked! I was out of the nonacademic track and I loved it.

Remember me talking earlier about my uncle and the handful of special teachers that believed in me and let me know that they believed in me? Well, had it not been for them, I don't think I would be where I am today. In fact, I know I wouldn't. As a child, my uncle loved me unconditionally and I always heard him tell me that I would grow up

to become a doctor some day. So when things got really tough for me, I would always hear him saying to me or to others around me “Gene’s going to grow up and become a doctor some day.” And you know what? It really did help me to get through the difficult times. And believe me, there were some difficult times. I also could not have made it without those teachers who always told me that I had the ability to be in the regular academic track. Guess what? I believed them!

In 1970 after I was placed back into the regular academic track, I was also selected to work in a pilot program that used students as residential aides with the younger students on campus. There were four of us selected to work in the program that year and all four of us worked in the program until we graduated from high school. I had a dorm with 16 boys and my job was to wake them up and make sure that they were dressed and ready for breakfast. After breakfast I was responsible for getting those that needed medication to the health center for their meds and then get them off to class. In lieu of monetary compensation for our services, we were given our own private rooms instead. And believe it or not, the private room was the selling point for all of us who participated in the program. We were the only four students on campus who had their own private rooms, and we were envied by the entire student body. Because we had demonstrated a strong work ethic, good leadership skills, and someone believed in us, all of us were offered full-time employment by the school after we graduated.

After graduation, in the fall of 1973, I was hired by the school and asked if I would like to work in a special program called deaf-blind. I knew then that my earlier high school work experience had helped me to explore whether or not I wanted to work in the field of special education. So I accepted the position and over the next eight years I received some of the best preparatory training for working in special education. I’m not talking about formal preparatory training but rather the day-to-day work experiences.

Shortly after I started to work at the Deaf-Blind Annex I realized that I was surrounded by a group of young people who were extremely bright, goal oriented, and who thought they could make a difference in the lives of each and every family we came in contact with. Therefore, it didn’t take me very long to realize that I loved the Annex culture and that I too wanted to continue to grow individually and professionally. So I decided that I wanted to attend college and to someday be in a position to help visually impaired people and their families achieve their goals. Finally, in 1975, while I was still working at the Annex, I decided that my goal was to graduate from The University of Texas at Austin and to passionately pursue a career that would be used to ultimately change the lives of people with blindness and visual impairment.

That goal ultimately led to my receiving a doctorate of philosophy from the University of Texas at Austin in 2000. I am now a researcher and rehabilitation consultant and was appointed by Governor Perry in April 2003 to serve on the Governing Board of the Texas School for the Blind and Visually Impaired, where lives of young people are indeed changed.

Creating Pathways for Children with Deafblindness - the NTAC/NFADB Parent Training

By Edgenie Bellah, Family Support, Texas Deafblind Project

Abstract: This article provides a brief overview of person-centered planning and shares three parents’ stories about how they are using the tool to plan for their child’s future.

Key word: blind, deafblind, family, person-centered planning, career education

When children have disabilities such as deafblindness, sometimes it is hard to envision their long-term future. Having information and connections to individuals who can serve as role models is helpful, but ultimately each family must create a personal dream for the future that is based on their loved-one's interests, talents and available community supports. There are a number of tools that have been developed to help families and significant people influencing the individual's life create a positive vision for the future. One such tool is person-centered planning as process often referred to as mapping because it creates visual images to reflect the person's life experience and path.

On September 18-20, 2003, I joined three other parents from Texas in Tampa, Florida for the annual parent workshop sponsored by The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) and National Family Association for Deaf-Blind (NFADB). This year's training focused on person-centered planning as a tool to help parents plan for all the transitions their child with deaf-blindness might experience from birth through adulthood. Person-centered planning is not new. As Keith Fansler, one of the parents from Texas, pointed out to me in a later conversation, parents create maps for all of their children's futures.

According to Dr. Beth Mount (1991), person-centered planning:

- Works to support the contribution of each person in local community life
- Finds and develops the gifts, strengths and talents of each person
- Develops a vision that expresses these gifts
- Builds a support group to make these ideals happen
- Builds a community network of acceptance
- Changes services to be more responsive to the interests of people

While there is much written about the benefits of person-centered planning, the most meaningful way to gain a true picture is through the words of parents who have already experienced this process. The first story below is written by Corry Hill, who is the Family Specialist for the Utah Deafblind Project and NFADB Region 8 Regional Director. Corry shared her story, written in 1994 after her family's initial experience, at the kickoff of the training. Her story inspired me to ask the parents from Texas who went through the training to share their experiences. Two of these parents are Keith Fansler of Amarillo and Melanie Knapp of Missouri City.

CORRY'S STORY

I am the mother of an adorable six-year-old daughter, Laurie Lynn Hill, who just so happens to have a dual sensory impairment and is multiply handicapped. Before I had experiences with mapping, I would introduce Laurie as someone who couldn't talk, walk, eat and who couldn't hear or see very well. Futures Planning helped everyone who works with Laurie and myself view her as a whole person with strengths as well as weaknesses.

Those people who have worked with Laurie have always been good, but prior to Personal Futures Planning (Maps), it felt like a disjointed effort. Each person was concentrating on what Laurie couldn't do or what she needed to learn in their own specific fields. For example, the OT's goals were written before she had met Laurie, written directly from a text book, not changed for two years, and not incorporated with anything else in Laurie's school day.

We were first introduced to futures planning at a deaf-blind conference in 1992. Our family attended a session learning about Maps and then the conference broke into small groups to actually make some maps. We had the privilege of using Laurie as the example. In attendance at that group were several people who worked with Laurie, both directly and indirectly, including her teacher, intervener and several service providers. We began by creating a Background Map. Laurie's intervener, her father and I were the major contributors because we had known her all her life. By the time that map was finished I felt the group begin to have some cohesiveness. We were at a common starting

point. Everyone in the room knew of Laurie’s struggle to live and we all looked at her with the “same eyes.” While creating the Relationship Map we were all pleased to discover the many people who worked with and cared for Laurie. I was especially pleased while the Preferences Map was being created to see everyone giving input. They knew Laurie better than I thought they did, and we came up with even more “things that work” than “things that don’t.” Service providers wrote down specific ideas to try that they didn’t know about before, things that someone else had success with. The Dream for the Future Map was the hardest for me to work on. It is difficult for me to dream for an uncertain future. Everyone in the room was very encouraging and urged us to dream high. We were very proud of our accomplishments as a group. Three years later a speech therapist commented that mapping session helped her greatly and was the best thing she had ever seen. Even though Laurie’s maps have been updated many times, I still have those original maps and cherish them.

After the mapping session, I noticed a change in all those who had been part of the process. Fences were down - it was no longer us against them, but a team with everybody an equal partner. The attitude toward Laurie was positive. That is, everyone treating her as a whole person and sharing ideas about how to achieve goals together.

KEITH’S STORY

The Fansler family has been in the deafblind business going on sixteen years now. My wife, Leslie, and I have been together for a little more than seventeen years. We have two sons. Our oldest son, Chance, is a junior in high school. Chance is a ranked fencer and on the varsity wrestling team. Preston, our youngest son, was born blind and is now carrying the deafblind label. Labels — you’ve got to love them. Preston loves the water and is a gold medallist bowler in the Special Olympics. He has several jobs, one of which requires him to swim for his paycheck. We are longtime members of Deafblind Multihandicapped Association of Texas (DBMAT) and NFADB. For several years, I served as Member-At-Large and Vice-President of DBMAT. I also have attended the NTAC-NFADB parent trainings since one of the earliest trainings in St. Louis.

This NTAC-NFADB parent training was a little different than the ones I attended in the past. They had me moderate our group’s mapping process. I had been to a session on mapping before, but we have never done it for our son, Preston. It was amazing to see how much information our group came up with for the lady who was picked to have her child be the focus of our mapping training. This was the first time our group had met. We were total strangers. I loved the experience I had with moderating. It let me see how easy it really is to build a program on a child’s strengths and not his/her weaknesses. Our group built a program for a total stranger based on her likes and dislikes. Just think of what you can do for your family member or even somebody you know. Being the moderator gave me the confidence I need to do a mapping on my son. If you think about it, we all do person-centered planning for ourselves. Leslie and I have done person-centered planning with our oldest son, Chance. To an extent, we have done it with Preston. We try to find jobs and activities that coincide with what he likes, not with things he does not like.

The only problem I see with mapping is getting everybody together at the same time, so it might take two or maybe more sessions. You might want to break it down into groups, like family and friends, professionals, church and community. Getting your person-centered planning ideas into the IEP can be a challenge, but it is a must. I hope to be starting a mapping process on Preston soon because I learned it is never too early or too late to do mapping. My advice to all parents is to map throughout your child’s life so you will know where you have been and where you are going.

MELANIE’S STORY

Christian was born in July of 1980, the second son to Gary and myself. We were told we might have a premature

birth, but never in my wildest nightmares were we prepared for what was to come. After his birth at 28 weeks gestation, Christian spent his first two years in the hospital. I can't even remember how many surgeries he had or how many times we almost lost him. As a result of his prematurity and long hospitalization, Christian had numerous medical difficulties. He is now 23 years old. He is deafblind. He is incredibly strong, and has a great sense of humor (Knapp humor). He also is a really good-looking guy. Christian has a wonderful big brother, Landon...and now a sister-in-law, Christi. Christian thinks Christi is HIS girlfriend. I am the Momma, and Gary is Dad. We have had tremendous family support over the years. Christian is in his last year of school. He has made AMAZING progress over the last three years. He understands a lot of sign language. We have had many years of incredible support from his educational team.

A few years ago, David Wiley and Craig Axelrod came to our home. We went through the person-centered planning process for Christian then. It was just the four of us that night. So many events have taken place in our lives and Christian's life since then.

What did I learn from my training in Tampa? Well, I volunteered Christian to be the focus person. While I was quite proud of myself, I realized during the process that since I was the only one that knew Christian, it was a very subjective mapping. The training did give me the tools to take on a better, less subjective mapping, and it was up to me to make it happen for real.

Upon my return home, I was determined to have a person-centered planning party. Gary and I were happy with how many people were able to make it. I invited the family that was in town: Landon and Christi, Mimi, Aunt Cheryl. A few members of my family were unable to come for the first meeting, but hopefully will jump on the wagon next time. Chantel Simon (Christian's caregiver) was there as was Ann Bielert (his intervener), Mrs. Parker (his classroom teacher), and Gloria Vaughn (his vision teacher through the years). I was ecstatic that Craig Axelrod, David Wiley, and Edgenie Bellah from Texas Deafblind Outreach at TSBVI wanted to help.

I think the mapping process went great. We had so much input from everyone, not just from me. The process was also therapeutic. There were a few tears and a lot of laughs. I definitely feel like the mapping was a success.

What came out of our first meeting is a plan. We have looked at what Christian would want, what he would want to do as work, where he would want to spend his time, and who he would like to spend it with. We have determined as a team what will work for him and what won't work. We have already put our plan into action. Christian now owns a small vending machine and has started training with it at school to learn how to stock it. When he graduates, we will move this one to his Dad's office. Who knows? He may become quite the vending machine entrepreneur!

OTHER RESOURCES

These stories are far from ending. Families will continue to build upon their initial dream through ongoing mapping. Just like you and I, the dream is ever evolving in response to our actual experiences and changing needs and interests. I want to thank each of the parents for sharing their personal stories about their recent learning experiences and for allowing me to tag along for the wonderful journey they are on with their families.

For a more detailed description of planning for adult life for individuals with multiple disabilities such as deafblindness, be sure to read the article, *When Planning for Adult Life, How is a "Life-style" Different than a "Program"?* by David Wiley on page 29. Families are also welcome to call the Texas Outreach program for assistance in developing a person-centered plan. Kate Moss and David Wiley have written *A Brief Guide to Personal Futures Planning, Organizing Your Community to Envision and Build a Desirable Future With You: a paper that provides an overview and step-by-step directions for the process*. The Outreach Program is also available to help with individual plans.

Keeping the Bar of Expectations High

By Brandy Wojcik, Discovery Toys Educational Consultant, Austin, TX

Abstract: Meet a young lady whose life speaks volumes about the value of self-advocacy at an early age. Parents and professionals alike will gain much from her story of a determined path toward a career choice.

Key words: blind, deafblind, personal story, career education, expanded core curriculum

I am a 23-year-old attending the University of Texas, majoring in Early Childhood and Special Education. I currently work two part-time jobs, one at St. Luke Infant Care Center and the other as an independent salesperson for Discovery Toys®. I frequently baby-sit for extra money and to gain valuable experience. In my spare time I enjoy playing my flute, reading, helping others succeed, and singing in my church choir. When I was approached to write this article, I was asked to respond to several questions: What guided me to make this career choice? What and who helped me arrive at my decisions? There is not a simple answer, as I believe many intricately woven experiences and special people got me where I am today.

Looking back, the first ten years of my life experiences played a large role in my success. When I was first diagnosed with Leber's Congenital Amaurosis, a counselor came to my home to talk to my mom and she said, "If you overprotect her now, you will have to overprotect her for life." It was then that my mom removed the pillows, and raised her bar of expectation for what I could become. For as long as I can remember, my blindness was never an excuse. I was taught that, yes, I was different, but this was no problem. Yes, I may have to do some things differently, but that was the key: differently I would still complete the task or goal. From as far back as I can remember, I was expected to play an active role in my family chores, in school, and in extracurricular activities, such as Girl Scouts. During my preschool years I began to learn braille while attending class daily, to clean up my room, to clear my place at the table and to respect others. As the years passed and I got older, the responsibilities increased, as did the expectations. I continued to do chores, along with homework and helping with my younger sister. I also started to take an active role in making decisions about my educational program.

During junior high and high school, many things remained the same but many things also changed. The thing that changed most dramatically was my school arrangement. Because I attended eleven different schools during the first twelve years of life, I had fallen way behind academically. There was no doubt I had the ability; I just lacked the resources to learn. When I completed fifth grade, I had twelfth grade comprehension skills but my other reading skills and math skills were on the second- to third-grade level. To help me catch up, the decision was made that I needed to attend the Texas School for the Blind and Visually Impaired (TSBVI). I already had a good foundation through doing chores at home, but now that I was older and living away from home, I learned to cook, clean, set goals, travel independently and be a part of the decisions made about me at a whole new level.

It was around this time when I became very active in extracurricular activities. I continued to be active in Girl Scouts, sharing the responsibilities of the troop's success. I began being active in sports, student council, choir, piano lessons, the Pal Program, and drama class.

Even though I attended every ARD since I was in third grade, I only contributed by giving my opinions on what was already decided for me. In sixth grade, my advisor began meeting with me before the ARD to let me have a say in what was being planned for my education. I think this was important because I started learning how to decipher if I wasn't happy about a decision because I didn't like it or I had a good reason for not agreeing with the ARD committee. It allowed me to be honest about my abilities and to take control of my life. In the eighth grade, I returned to my public school. When I started getting concerned that I wasn't receiving the education I needed to be successful in college, I

called my own ARD to advocate that I be on an equal playing field as my sighted peers. I didn't care what type of work I needed to do; I wanted a fair chance to compete with them to attend college. As part of the ARD committee, we made the decision for me to return to TSBVI. Once I asked to be treated equally and to have high expectations, I got it. I think in many ways, because I had to work so hard to receive a good education, it means more to me than one can imagine.

In sixth grade, I also began volunteering so that I could get work experience and to compete in the annual community service award. The first volunteer experience I had was at Magic Years Day Care where I worked in the infant room assisting the teacher in feeding, changing, and entertaining the children. I loved this work and my dreams of becoming a teacher began to blossom. I figured out that I wanted to teach babies, but I didn't know how much I wanted to do this until high school. That was when I learned that to make the difference I was wanting to make, I would need to teach children with special needs. It was the Pal Program that fostered this portion of my goal. The Pal Program is where older students were paired with elementary students to take them places on campus, help with homework, and in general be their mentor.

During high school, I participated in the TSBVI Dual Enrollment program, where students attend a portion of the day at a local high school and a portion of the day at TSBVI. I became active in theater, and later in band, while learning to play the flute. As you may or may not know, in high school, teens are encouraged to begin thinking of life after school. I knew college was a must for my goals, and I set my standards high and arranged my high school classes to give me the educational experience I needed to reach my goals. I took classes such as Home Economics and Child Development. I also participated in a summer work program where I worked at a local child care center sharing the classroom responsibilities of caring for the children. During the summer work experience, I also lived in an apartment with two other teens who were participating in the program. This work experience only strengthened my desire to teach. I graduated valedictorian of my class at TSBVI, and was ranked 57th out of 430 at McCallum High School.

While all the activities and expectations I have shared in the previous paragraphs played a large role in my choices and goals, a few things made a significant difference in who I am today. The first is the attitude people had about my blindness, that is, "no big deal." The second is the level of responsibility I was given and expected to keep. My involvement in Girl Scouts for twelve years was also a key factor; for it was here I learned to set my own goals, keep a calendar, interact appropriately with peers and adults, and to do my part. I have also always been held accountable for my actions — good and bad. I truly believe it is that which molded me to be who I am.

As an adult, I continue to set new goals to achieve. I now know I want to work with infants with special needs, and have found the college path to get me there. I have had two kidney transplants and took care of my own home dialysis while waiting for the second kidney. I am currently caring for my younger sister who lives with me while I independently clean my house, shop and cook my own food, attend work, and school. I am active in my church helping to teach Sunday school, taking Bible classes, taking my turn in cooking for fellowship events, and baby-sitting.

I am often asked how I got into selling Discovery Toys®. I decided to sell them when I needed some toys for the children I cared for at my home. I quickly discovered it was fun and easy, and I could work just one day care job instead of working two. The best part about selling is that I feel like I'm able to help parents with children of all abilities.

The one thing that had the most impact on shaping my decisions and goals today is what that counselor shared with my mother when I was just a baby. If she hadn't told her to let me have normal life experiences, I may not have ever made it this far. I want to be that teacher for others, guiding them to help their children to be all they can be in all aspects of life.

I'd like to thank the people who played valuable roles in my growth and independence: my mom for insisting from the beginning that I be normal, living out my dreams; Lisa Birr, my first blind adult role model

and teacher; Jan Walker, my first braille and O&M instructor when I was three years-old; Debra Sewell, my teacher at TSBVI, for helping me improve my braille skills and catch up academically; Nancy Voots who was my advisor and teacher throughout the seven years I was at TSBVI; Robyn Koenig, residential instructor, for continuing the expectations my mom started; Elise Ragland, my Girl Scout leader, friend, other mom, and sales director in Discovery Toys®; and Helen Weiker, my Boss and director at St. Luke, for insisting I play an equal role in my work, and for being flexible in adapting the work site by doing things such as putting braille labels on the children's storage bins. Thank you all for always being there!

I love helping others, and if any readers wish to talk with me about my story or to get more information about Discovery Toys® you can reach me at 512-453-0975 or <brandy@discoverytoyslink.com>. You can also check out my website at <www.discoverytoyslink.com/brandy>.

Active Learning and the Exploration of Real Objects

By Stacy Shafer, Early Childhood Specialist, and Ann Adkins, Education Specialist,
TSBVI Visually Impaired Outreach

Abstract: This article describes some of the techniques of Dr. Lilli Nielsen's Active Learning Theory.

Key Words: blind, deafblind, Active Learning, Lilli Nielsen, real objects, Little Room, resonance board, position board, play

Editors Note: In the last edition of See/Hear, we printed "An Introduction to Dr. Lilli Nielsen's Active Learning" and promised to provide additional information on active learning in each issue this year. In this issue, we'd like to examine some of Dr. Nielsen's learning strategies and the importance of using real objects. We would also like to hear from others who have used active learning, and encourage you to contact Stacy Shafer at <StacyShafer@tsbvi.edu> or Ann Adkins at <AnnAdkins@tsbvi.edu> to share your experiences.

Visually impaired children learn by exploring and manipulating the objects in their environment and by comparing new objects to familiar ones. They need as many experiences as possible with *real* objects and textures. Hands-on experiences with a variety of objects, made out of as many different materials as possible, allow students to work on a variety of skills and learn about their environment. Concrete experiences with real objects also facilitate concept development. It is important to give students ways to actively impact their environment and teach them to be active participants in their world instead of passive recipients of stimulation from adults. The active learning techniques developed by Dr. Lilli Nielsen provide excellent opportunities for visually impaired students to gather information through the exploration and manipulation of real objects. Dr. Nielsen's approach encourages children to be *active* learners, and helps them discover that they can control events in their lives.

EQUIPMENT

Some of the active learning equipment and materials that we have observed include:

The Little Room

The Little Room is described in detail in Dr. Nielsen's book, *Space and Self*, and in the article in the last edition of *See/Hear*. It is a piece of equipment that provides students with a safe environment for independent play and exploration. Many children are more willing to tactually explore objects when they are in control of an activity and can anticipate what might happen. The objects in the Little Room are attached with elastic and go back to their original

positions when the child lets go of them, enabling him to find them again and repeat an action as quickly and as often as he wants. It gives students the opportunity to work on object exploration and manipulation, object comparison, object permanence, cause and effect, spatial concept development, problem solving, independent play, recognition, anticipation, sensory integration, and spatial memory. The Little Room also provides the opportunity to learn about the different materials from which objects are made (paper, leather, wood, metal, etc.) and the different attributes of objects (size, weight, temperature, etc.). As students experience these different objects and learn about their specific characteristics, they will discover that some objects are better for some activities than others. They will learn that some objects make better sounds when batted at than others, some are better for mouthing, some are more interesting to touch, etc. Although the Little Room is an independent activity, it MUST be supervised at all times.

The Position Board

This is a piece of pegboard to which objects are attached with pieces of elastic and is also described in *Space and Self*. It may be used as an independent activity if the position board is placed so it will remain stationary, or it may be used with an adult. It can be attached to a student's wheelchair tray, attached to a wall, or placed on the floor or table. Like the Little Room, objects should remain in the same position to encourage the development of object permanence, and the elastic attached to the objects needs to be long enough for students to be able to bring the objects to their mouths. Be sure to include objects with different weights and textures.

The Scratching Board

This is a piece of wood with different textures attached to it. These textured squares are approximately 3" X 3". Examples of textures to include are: leather, carpet, cork, shiny wrapping paper, packing "bubble" sheets (if there is not a danger of the student tearing off a piece and getting it in his mouth), corrugated paper from a box of chocolate candy, shiny ribbon, suede, etc. Fine screening, like tea strainers or cooking strainers, can also be used if the edges are covered to prevent injury. The scratching board can be attached to a student's tray or positioned so that it can be used while the student is lying on the floor, with either his hands or feet. The Scratching Board can be stabilized so it is an independent activity.

The Tipping Board

This is a board that is fixed in an upright position. Hang objects from the top of the board so that students can receive sensory feedback by batting at them. Again, it can be positioned so that a student can use both his hands and feet. Some objects to consider using include: shiny bead necklaces, strings of interestingly shaped beads, chains (such as those used in the 70's as belts and necklaces), bells, a plastic or metal slinky, wooden spools strung on cord, etc. Inexpensive necklaces can be restrung with nylon fishing cord or dental floss to prevent breakage. The Tipping Board is an activity that students can do independently, with supervision, if the board is stabilized.

Vest with Objects

The Vest is like a cummerbund with Velcro. Objects and interesting textures are attached to it for students to explore independently. Headliner fabric may be used instead of Velcro to reduce the possibility of abrasions.

The Resonance Board

Playing on a resonance board can be a very rewarding activity for students, providing them with sensory input from the vibrations created by their play. Position the student on the resonance board with several interesting objects around him to encourage him to explore his immediate environment. Playing on the resonance board can be an independent activity, or it is an activity that could be shared with an adult or another student. The child should be on the Resonance Board when using a Little Room.

All of the activities described above encourage students to use their hands to explore their environments. Visually impaired students need repeated opportunities to tactually explore and examine real objects every day. They need a variety of experiences that require *active* responses. Additional information on active learning can be found in Dr. Nielsen's books, *Space and Self* and *Are You Blind?*. These books also include information on suggested objects to use with the activities. The student's educational team should work together to choose appropriate objects. Objects should be pleasurable, graspable, and have tactile, auditory, and visual qualities. Real objects from everyday experiences and daily activities are recommended because they can provide more meaningful and rewarding experiences than toys. Toys and commercially available objects are often made of plastic, and plastic provides little information that is tactually meaningful for visually impaired students. Objects should also be presented in such quantities that the child will have the opportunity to choose, compare, and play counting and sequencing games. They should also vary in weight and texture. Caution is advised because some objects are not appropriate for use with all students. Teams should ensure that all materials and boards used in active learning activities are splinter free, that rough edges are covered with heavy layers of masking or packing tape (especially pegboard), and that any paint, acrylic, or finishing agents used are nontoxic. Even though these are independent activities, they **MUST** be supervised at ALL times.

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What's Up with Interveners in Texas?

By Jenny Lace, Education Specialist, TSBVI Deafblind Outreach

With help from Jim Durkel, Statewide Staff Development Coordinator, TSBVI Outreach

Abstract: This article discusses training for Interveners in Texas and shares key components of intervention.

Key Words: Deafblind, intervener, intervention, training, No Child Left Behind, courses, portfolio

INTERVENER MODEL GROWING IN TEXAS

Did you know that fifty-six interveners have been identified in the state of Texas? The Intervener Model is recognized by the Texas Education Agency and Texas Deafblind Outreach Project as a supplemental service or modification consideration in the IEP (see "Documenting Instructional Considerations for the Student with Deafblindness" <<http://www.tsbvi.edu/Outreach/deafblind/AppIDBInstructional-Modifications.doc>> and "IEP Quality Indicators for Students with Deafblindness- Related and Supplemental Services" <<http://www.tsbvi.edu/Outreach/deafblind/indicators.htm>>).

An intervener is a paraprofessional who works one-on-one with a deafblind student and who receives training in the communication methods and modifications needed for an individual deafblind student to access information in their environment. It is not uncommon for deafblind children to need one-on-one support with someone they have bonded with and trust. If a deafblind child cannot access information going on at a distance and is left alone with no means to predict and anticipate events, the result can be withdrawal, aggression, and/or self-stimulating behaviors. It is important to remember that "alone" for a deafblind child can with limited vision and hearing can also occur in a group or in the middle of a busy classroom without direct intervention.

Go to <<http://www.tsbvi.edu/Outreach/deafblind/intervener.htm>> "Interveners for students with Deafblindness in Texas: A Model of Individual Support to Provide Appropriate Access to Education for Students who are Deafblind"

to find out more. This document includes information about:

- What is an Intervener?
- The Unique Needs of a Student who is Deafblind
- How Interveners Differ from Other Typical Support Staff
- Who Should Have an Intervener?
- Sample Intervener Job Description
- Important Issues for Schools Using an Intervener
- Administrative Checklist
- Bibliography of Additional Materials on Interveners

HOW DO INTERVENERS GET TRAINING?

Since deafblindness is a low incidence disability, the educational staff may need support and training in methodologies that address the unique needs of a dual sensory impaired student. When both vision and hearing are distorted, learning cannot occur from a distance or incidentally. The near senses must be used to experience learning and to develop concepts about how things work in the world. It is not uncommon for staff to need training in specialized communication techniques and training in how to implement modifications unique to the student's combined hearing and vision losses that will assist the student in accessing environmental information.

In Texas, interveners are asked each year to fill out an "Intervener Self-Assessment of Competencies Needed to Work with Students with Deafblindness" <<http://www.tsbvi.edu/Outreach/deafblind/intervener-self-assess.doc>> to identify their training needs. Their current training priorities are shared with their immediate supervisor, Texas Deafblind Outreach, and their regional deafblind specialist at the education service centers. This information is used to address training plans for the current year.

Training Options for Interveners and Teams

Training options available to Interveners and teams serving deafblind students in Texas, include:

- Annual Statewide Intervener Team Training offered by the Texas Deafblind Outreach
- Regional workshops on deafblindness offered through the regional deafblind specialists at the education service centers
- On-site technical assistance and direct training with the intervener, team and student can be requested from the regional deafblind specialists and the Texas Deafblind Outreach
- District level in-service training for intervener teams can be requested and provided by Texas Deafblind Outreach
- Resources on deafblindness (including articles, books, video tapes and DVDs) are available through the regional deafblind specialists at the education service centers and Texas Deafblind Outreach.

Checkout:

- "A Guide to Resources on Deafblindness for Families, Community Members, and Professionals in Texas" <<http://www.tsbvi.edu/Outreach/deafblind/guide.htm>>

- “Incredible Intervener Idea!” <<http://www.tsbvi.edu/Outreach/deafblind/ideas.htm>>
- “Intervener Competency Resources Matrix <<http://www.tsbvi.edu/Outreach/deafblind/matrix.doc>>
- Courses and distant learning through institutes of higher education (see *Resources* at the end of this article)

2003 STATEWIDE INTERVENER TEAM TRAINING

Texas Deafblind Outreach supports training with at least one professional on the intervener’s team to promote team competence in deafblindness and effective supervision and support to the intervener. An annual statewide Intervener Team Training was held November 21-22, 2003 in Austin, Texas with thirty-one interveners and thirty-two team professionals attending. Intervenors completed their “Intervener Self-Assessment of Competencies to Work with Students with Deafblindness” prior to participating in the training. The team brought Student Profiles to assist them in applying training strategies to their deafblind student’s individual hearing loss, vision loss and additional needs. Teams were asked to participate in a follow-up study on the effectiveness of training and documentation of the impact of the Intervener Model on student progress. They were sent home with an “Annual Student Assessment” <<http://www.tsbvi.edu/Outreach/deafblind/annual-student-assessment.doc>> to complete in the years 2003, 2004, 2005 to track the progress of students who are assigned an intervener.

Joyce Olson, Coordinator of the Provincial Outreach Program for Students with Deafblindness in British Columbia, was the presenter at the 2003 Annual Statewide Intervener Team Training. Participants experienced activities under simulation in roles as deafblind students and Intervenors. Through these activities under simulation, partners learned:

- The Intervener Motto: Do With Not For
- The Goal of an Intervener: To ensure that the deafblind student is an active participant and informed learner in all activities.

Joyce’s training focused on Four Key Components of Intervention (adapted from the work of John and Jacquie McInnes of Brantford, Ontario):

Anticipation

The intervener must provide the person with deafblindness with enough information to allow them to anticipate coming events for the individual (e.g. touch cues, environmental cues, object cues, picture cues, signing, print, speech, etc.). Once the person has sufficient information to anticipate what is happening the intervener should make the individual aware of any choices that may be made, so that they can continue to increase their independence.

Motivation

The intervener will always provide motivation. In the early years it will be the intervener rather than the activity that will be the motivator. Later on the intervener’s skill and enthusiasm for the activity will play a large part in the deafblind person’s desire to learn, and to practice old skills.

Communication

Communication is the key to everything that an individual with deafblindness does. Through the use of a variety of communication modes, based on the needs of the individual, the intervener provides enough undistorted information so that the person with deafblindness can make appropriate decisions and carry them out.

Confirmation

A person with deafblindness may not be able to gather sufficient feedback from their environment to know how successful or unsuccessful they have been in attempting to do a specific activity. The intervener must provide this information so the individual knows what effect their actions are having on the world around them.

- Establish a trust bond with the person you are intervening for.
- Participate together in activities you both enjoy.
- Show respect.
- Provide opportunities for problem-solving.
- Structure activities for success, while allowing the opportunity to learn from mistakes.
- Be expressive. Use lots of facial expression, body language and at times exaggerate your actions. A toy car may not be of interest to a child, but the way you interact with it will be.
- Be enthusiastic. Have fun with what you are doing.
- Offer choices whenever possible and respect that choice when it is made.
- Involve the person in the whole activity. Involve them in gathering the needed materials, so they can learn where things are kept. Do the activity with them, not for them. Clean up is an important part of an activity.

Interveners attending the training had time to network with each other and share their individual experiences in their roles as interveners. Email addresses and contact information were exchanged for the opportunity for continuing a dialogue with one another.

PORTFOLIOS TO DOCUMENT INTERVENER SKILLS AND TRAINING

With the enactment of the Federal “No Child Left Behind” legislation addressing quality public education, there are new guidelines concerning the qualifications of paraprofessionals <<http://www.ed.gov/policy/elsec/leg/esea02/pg2.html#sec1119>> and <<http://www.tea.state.tx.us/taa/comm050803.html>>. During the 2003 Statewide Intervener Team Training, Jim Durkel from TSBVI Outreach provided the following guidelines for interveners to use a portfolio to document their skills and training <<http://www.tsbvi.edu/Outreach/deafblind/portfolios.htm>>.

What is a portfolio?

A portfolio is a collection of work. It is easiest to imagine the portfolio for an artist or a writer; these portfolios would contain photographs of the artist’s works or samples of the writer’s writing. It may be a little harder to imagine how a portfolio for an intervener would look. Before discussing how a portfolio for an intervener would look, let’s look at why an intervener might want to create a portfolio.

Why create a portfolio?

A portfolio is evidence of your skills and talents as well as a record of training you have completed. The portfolio can be used as a “scrapbook” to help you remember and reflect your successes, it offers you an opportunity to think about ways to improve your skills, and it can be used as proof of your abilities and accomplishments during annual performance reviews or when interviewing for a new position. Many colleges are using portfolios to document life accomplishments and are offering their students course credit for these accomplishments.

What can be in a portfolio?

Portfolios can be as simple or as elaborate as you wish. It is important that materials be organized in some way so that proof of an accomplishment is easy to find and is clearly labeled. A portfolio is not merely a collection of materials that have been stored willy-nilly in a cardboard box. Nor does a portfolio need to contain an example of everything you have ever done. A portfolio is an organized collection of samples of your accomplishments designed to showcase your skills.

These samples can take many forms. For example, a portfolio may contain a copy of a post-secondary degree or copies of certificate of attendance from workshops or conferences. The portfolio might contain videotape segments of you engaged in an activity with a student. It might contain a copy of materials you adapted for your students. Just keep in mind that the portfolio is a record of your work, not of the student's work. (Though you can create a separate student portfolio to document your student's accomplishments and progress.)

PROGRAMMING

Here is a partial list of what might be in the portfolio. This list is not necessarily complete!

A summary of your credentials/qualifications/etc. which might include:

- Your resume (you might want to include job descriptions from relevant experiences)
- Results from any written exams you have taken relevant to being a paraprofessional in the public schools
- Copies of post-secondary degrees
- Copies of school transcripts (possibly including high school), especially showing relevant classes, like sign language or child development (you may want to include course syllabi to highlight the content of the classes)
- Certificates of attendance for workshops and/or conferences (you may want to include the agendas for these trainings to highlight the content of the training)
- Professional certificates, like those for sign language interpreters, Braille transcribers, or day care providers
- Descriptions of relevant personal experiences, such as having a child of your own with disabilities
- Copies of previous work performance evaluations
- Letters of recommendation from employers (especially supervisors or professionals who directed your work)
- Copies of any relevant honors or awards

Written samples of your work, which might include:

- Data collection sheets that highlight how you collected and organized data
- Samples from a school-home communication book (make sure you have permission from the child's parents and other relevant school personnel, if necessary)
- Communication with other team members
- Articles you might have written for a newsletter
- Handouts you might have developed for an in service training or workshop

Examples (either the material itself or photographs) of materials you have created or material adaptations you have made such as:

- Samples of materials in Braille
- Samples of communication boards
- Samples of adapted games
- Samples of experience books
- Samples of calendar systems
- Adapted recipes
- Bulletin boards you created
- Adapted worksheets

Samples of the student's work that reflect your role as an intervener, including:

- A hard copy of TTY conversations with the student that highlights your support of the student's performance
- An experience story written by the student that includes references to you and your role during the experience

A videotape or photographs of you supporting student success in some activity, for example:

- An independent living activity, such as grocery shopping or cooking
- The student ordering an item at a fast food restaurant
- The student interacting with peers
- The student engaged in a recreation/leisure activity
- The student engaged in an academic (reading, math, science, etc.) activity
- The student in PE
- The student using some piece of adapted equipment, including low vision aids, mobility devices, note takers, assistive listening devices, communication devices, etc.
- The student engaged in a recreation/leisure activity

Samples that demonstrate your competency in some procedure or instructional technique, for example:

- Video tape of you interpreting for the student
- Video tape of a conversation with the student that highlights your skills at facilitating the interaction
- Video tape of you checking hearing aids or assistive listening devices
- Video tape of you acting as a sighted guide for your student
- Video tape of you providing various levels of prompts and reinforcements
- Video tape of any medical procedures you have been trained and authorized to conduct (such as tube feeding). You might want to include written evidence of the training.
- Video tape of you implementing positioning and handling techniques you have been trained and authorized to do. You may want to include written evidence of the training.

- Video tape of any sensory integration activities (such as brushing) that you have been trained and authorized to do. You may want to include written evidence of the training - again, get parent permission for any videotaped samples!

Evidence of your thinking about your role as an intervener, for example:

- Excerpts from a journal where you reflect on the student's progress and what you might do, keep doing or change
- Excerpts from team meetings (with permission from other team members) that highlight your suggestions/ thoughts
- Reflections on some article you read/workshop you attended/video tape you viewed that gave you some ideas about something to try with your student
- A professional development plan for yourself

Some hints for organizing the portfolio

- Consider making an index for the portfolio. The index might follow the recommended competencies for an intervener.
- Consider using a three-ring binder for as much of the material as possible. Where video tape is used, make sure the video tape is clearly marked with a reference to the competency or skill demonstrated on the tape.
- If you are including materials that don't fit in a three-ring binder, consider storing all the materials together in a storage box.
- The portfolio is not static. You can add new material and take out old material that is no longer representative of your work.

If you are an intervener (paraprofessional, teacher aide, instructional assistant working one-on-one with a deafblind student) in Texas and need more information on: resources on deafblindness, technical assistance, training opportunities, self-assessment of competencies in deafblindness, participation in a study on the impact of the Intervener Model on student progress, or getting on a mailing list contact Cyral Miller, Director of Outreach, at <CyrMiller@tsbvi.edu> or (512) 206-9242.

RESOURCES

Courses and Distant Learning on Deafblindness through Institutes of Higher Education

<<http://www.tsbvi.edu/Outreach/deafblind/db-university.htm>>

College and University Programs

<<http://www.tsbvi.edu/pds/universities.htm>>

Conferences, Courses, Events, Seminars, & Workshops Throughout the World about Deafblindness

<<http://www.deafblind.com/courses.html>>

Cochlear Implants

Jim Durkel, CCC SLP/A and Statewide Staff Development Coordinator
Texas School for the Blind and Visually Impaired Outreach Program

Abstract: This article describes the cochlear implant device and discusses the considerations for candidacy for an implant, benefits and limitations of an implant, controversies and problems, and specific issues when thinking about implants for people with deafblindness.

Keywords: deafblind, cochlear implant, amplification, hearing aid, hearing loss, deafness

WHAT IS AN IMPLANT?

A cochlear implant is a device used to make auditory information available to people with some types of hearing losses. The degree of information an implant can offer may be better than what can be achieved using conventional hearing aids. The cochlear implant can be considered a different type of amplification. It is not some type of “corrective surgery”.

If you would like to hear a simulation of what speech through an implant may sound like, go to <http://www.bsos.umd.edu/hesp/zeng/simulations.html>. Remember, this is a simulation and the actual listening experience of the user may be different. But you will hear that hearing through an implant is not “restored”. Instead, we are giving the implant user an opportunity to have access to information he or she did not have before.

The implant consists of internal (implanted) and external parts.

Implanted is an array of electrodes (fine wires) that are inserted into the cochlea. These electrodes deliver electrical impulses to the nerve fibers that run into the 8th cranial or auditory, nerve. Early cochlear implants (25 years or so ago) had a single electrode (or channel). Modern implants can have as many as 22 channels. Please note: the electrodes are implanted into the cochlea, not the brain. A cochlear implant does not involve brain surgery!

Also implanted is a receiver/transmitter. This part of the implant is implanted just under the skin behind the ear and is used to conduct information between the electrodes and the externally worn part of the implant.

Externally, the implant has a microphone, a speech processor, and a transmitting coil. The microphone takes in sound and the speech processor converts the sound into electric energy. The transmitting coil is worn on the outside of the skin behind the ear. A magnet attaches the external transmitting coil to the internal receiver/transmitter. The transmitting coil and the receiver/transmitter serve to convey information from the outside of the ear to the electrodes inserted into the cochlea.

The speech processor may be worn on the body, similar to a body hearing aid, or behind the ear, similar to a behind the ear hearing aid.

The role of the speech processor is to take auditory information, change that information into electronic form, and then send the information to the various electrodes implanted in the cochlea.

CANDIDACY FOR AN IMPLANT

Who is a candidate for an implant? There are recommendations but not legal requirements. A general bottom line seems to be that individual physicians can use their own judgment when deciding to perform an implant. Insurance reimbursement may not occur if the physician does not follow recommended practice, however.

In general, here are some recommendations and considerations for candidacy:

- The implant recipient be at least 12 months of age.
- The recipient has a profound bilateral sensorineural hearing loss.
- The recipient has tried and had little success with conventional hearing aids.
- The recipient should not have significant residual hearing nor receive good benefit from conventional hearing aids.
- The recipient and/or the recipient's family has realistic expectations for outcomes following implantation.
- The recipient and/or the recipient's family is able and willing to participate in all follow up appointments related to checking, maintaining, and adjusting the implant.
- The recipient and/or the recipient's family is able and willing to follow up on recommendations for speech/language/listening therapy in order to get maximal benefit from the implant.
- The recipient does not have damage to the 8th cranial, or auditory nerve.
- The presence of other impairments, especially cognitive delays, can impact the benefit a candidate may receive from an implant.
- In general, the less time that passes between the diagnosis of a hearing impairment and the implantation, the better implant recipients do. This consideration may need to be weighed against giving the recipient sufficient time to try conventional hearing aids and the recipient being at least 12 months old.
- Meningitis can result in bone build up in the cochlea; waiting too long after this condition may make inserting the electrodes difficult.
- In general, recipients who had a history of normal hearing have quicker initial success with an implant than recipients who have no prior listening history.
- The implant process requires general anesthesia; this may be a risk or be undesirable for some potential recipients.

BENEFITS AND LIMITATIONS OF AN IMPLANT

Not all implant recipients end up with the same auditory, speech, and/or language skills. Unfortunately we can't totally predict future levels of success before implantation. Some implant users are able to use the implant so well that they can carry on open-ended conversations over a telephone, a very difficult listening situation. Other implant users, however, may be limited to receiving some general environmental information through the implant.

It is important to state that an implant does not "cure" hearing loss. Successful implant users who had hearing and lost it report that listening with an implant is not the same as listening with unimpaired hearing. An implant is not restorative!

After the implant surgery, there is a need for regular and frequent follow up to ensure that the implant is working and that device has been programmed to deliver the most benefit to the implant user. There are different coding strategies the processor can be programmed to use to break apart auditory information and deliver it to the electrodes. The best coding strategy for one user (the strategy that provides the best speech discrimination) may not be the best for another user. And the best strategy for one user may change over time. Only through on-going assessment and reevaluation of the implant can this strategy be determined. At the least extreme, a processor may be providing little or no benefit because of an inappropriate coding strategy. At worse, the strategy may result in sensations of pain to the

user and result in a total rejection of the implant.

In addition to follow up for adjusting and setting the device, there is a need for intense training (speech, language, and listening) for the recipient to learn to use the information provided by the implant. A speech-language pathologist, a teacher of the deaf or hard of hearing, and/or an audiologist can best provide this training.

Wearing an implant does not necessarily mean that sign language should not be used. It may be that an implant user prefers sign as an every day communication mode. Or an implant user may want sign when learning new concepts and words or when in group or lecture situations. These are all difficult listening situations and even experienced implant users may want visual or tactual communication support.

One training technique for learning to use information from an implant “sandwiches” visual (or tactual) and auditory information. So, a word might be given in sign, then repeated orally only, then again in sign. This helps the learner associate what he or she is hearing with what he or she already knows. The sandwich can work the other way, too. That is, a word is given orally only, then in sign, then orally only again. It is so important to remember that the implant is not a cure; it is a tool that can support learning but it does not replace good teaching.

There needs to be a strong commitment for the implant to be of any benefit. An implant that is broken, has dead batteries, or is not consistently worn will provide no benefit.

CONTROVERSIES AND PROBLEMS

There has been some controversy in the Deaf culture about the use of implants. Some Deaf feel that an implant is an intrusive medical procedure and is done to “fix” what is perceived by the Hearing to be a medical problem. These Deaf feel that deafness is not a medical problem requiring this type of solution. On the other hand, most children with hearing loss have Hearing parents who would like their children to use speech and hearing to communicate. These are very emotional issues! You can read the NAD (National Association of the Deaf) position paper on cochlear implants at <<http://www.nad.org/infocenter/newsroom/positions/CochlearImplants.html>>.

There is a report of increased risk for contracting meningitis following implantation. (For more information, see <<http://www.tsbvi.edu/Outreach/seehear/winter03/fda.htm>>).

A cochlear implant can be disrupted by exposure to static electricity.

The external components of the implant can be removed and normal bathing and swimming will not damage the internal components. Internal components may be damaged by scuba diving.

DEAFBLIND SPECIFIC ISSUES

There are two considerations when thinking about implants for a person with deafblindness.

First, one of the main benefits for implant recipients who are sighted is better communication because of combined auditory and visual information during lipreading. Individuals with deafblindness may not receive this benefit.

Second, most implants in America are unilateral. That is, only one ear receives an implant. That means that the typical implant user cannot localize sound. This has profound implications for orientation and mobility training. It would be easy to overestimate how safe a high-level implant user really is when making street crossings while relying just on hearing.

Because the implant is unilateral, listening in noise may be quite a problem. Cochlear implants can be used with assistive listening devices to compensate for this.

Some implant centers are starting to provide implants to both ears but this is not yet a common practice in the United States.

RESOURCES

A great resource is “Cochlear Implants: Navigating a Forest of Information... One Tree at a Time” by Debra Nussbaum from the Laurent Clerc Deaf Education Center at Gallaudet University in Washington DC. This document can be downloaded from <<http://clerccenter2.gallaudet.edu/KidsWorldDeafNet/e-docs/CI/index.html>> or call (800) 526-9105. This document contains loads of information as well as additional resources. The document is in English and in Spanish.

TCB Ending Its 72-year History

Terry Murphy, Executive Director, Texas Commission for the Blind

Abstract: A discussion of TCB changes resulting from agency consolidation; a review of an inspirational article about services for blind children in Tibet.

Key Words: blind, Assistive and Rehabilitative Services, DARS, consolidation, accessibility, self-confidence.

The last months of 2003 at the Texas Commission for the Blind, as you would suspect, have been unlike any others in its 72 years. Our staff has continued to provide top quality services to Texans who are blind, while simultaneously participating in the abolishment of TCB as a state agency. By the time this Winter *See/Hear* issue is published, the merger of rehabilitation services, services for blind, services for the deaf and hard of hearing, and early childhood intervention services into the Texas Department of Assistive and Rehabilitative Services will be well on its way. (You can bet the new state agency will soon be known by its simplified acronym, DARS.)

The projected date for creating an operational DARS is by January 30, 2004. HHSC’s transition plan states that it will seek to maintain the identities of key service areas (such as blind or deaf services) to minimize confusion among clients looking for and receiving such services. Exactly what that means in the way of establishing offices or units has yet to be clarified.

For you readers who contacted our agency to voice your concern about the accessibility of information published by HHSC thus far during consolidation activities, I have some encouraging follow-up. In recent conversations with various HHSC officials, I had the opportunity to share concerns about the consolidation’s effects on the Commission’s blind employees and other blind individuals interested in the transition. This issue received quick attention and I am confident that the new enterprise led by HHSC is working diligently toward making jobs and information more accessible to Texans who are blind and other Texans who depend on alternative media and assistive technology to read.

This is the last article *See/Hear* will receive from me in my capacity as the executive director of the country’s top-ranking independent agency for the blind. I wanted somehow to sum up the most important accomplishments of the Texas Commission for the Blind over its long lifetime of service, but I soon gave up because it would require a lengthy book. Instead, I’m choosing to once again pass on a bit of inspiration I received from others who also have made a career working in the field of blindness. It’s in the sharing of messages of hope and encouragement that I find the most satisfaction.

One such inspiring article sent to me months ago made its way into “that” stack in my computer—the ones I save to wander through from time to time when I need a lift. The short article appeared in the *The New York Times* in September and was written by Jim Yardley about a lady named Sabriye Tenberken, who happens to be blind. Yardley writes about Ms. Tenberken’s school for blind Tibetan children in the land she has adopted where she and her partner, Paul Kronenberg, also run Braille Without Borders. The moving details talk about Ms. Tenberken’s distress at the lack of learning opportunities for the children when she first visited Tibet several years ago and her determination to improve the situation. She first tried to get a job with different international aid groups, but she says she was told that blind people were prohibited from doing “field work” and that there wasn’t anyone to “take care of her” in Tibet. This attitude didn’t surprise her after finding four- and five-year-old blind children in her travels who had yet to be taught how to walk! Having come from a German family and a high school for the blind that had encouraged her to discover her own boundaries, Ms. Tenberken’s determination to be an agent of change became even stronger. The article goes on to talk about how she is now a role model for 29 Tibetan students, ages 4 to 21. In August, the group went white-water rafting, and they plan to climb a nearby Himalayan peak next year! It reminded me of the activities our own blind children’s specialists and transition counselors plan with youths here in Texas to counter society’s lower expectations.

The main reason I saved the article was one paragraph at the end that bears reading again and again: *The main goal [of Ms. Tenberken] remains instilling self-confidence and self-esteem so that blind children will “not be embarrassed anymore.” A blind child, she notes, will never be able to drive a truck. “But they can read and write in the dark,” she said. “And who can do that?”*

What a neat way to declare their “special-ness” when talking to young children who are learning to read and write braille. In fact, what a neat way to verbalize the value of knowing how to read and write in the dark, regardless of a person’s age.

The emphasis on the value of braille and the teaching of braille has made a dramatic turnaround in Texas in the last few years. The Texas Commission for the Blind ensures that learning braille is available and encouraged as a core skill. TCB’s rehabilitation teachers are required to have the ability to teach, read and write all aspects of Grades I and II Braille. In November, the draft VI standards that form the basis for the Braille and VI Professional competency testing for Teachers of Students with Visual Impairments, require teachers of students with visual impairments to know how to read and produce uncontracted and contracted literary braille and Nemeth Code.

I have learned much during my 30 plus years at TCB simply by observing confident, successful professionals who are blind. Without exception, they don’t drive trucks, but they sure can read and write in the dark!

The Evolution of the Texas School for the Blind and Visually Impaired in the 21st Century, Part Four

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

Abstract: A discussion of the comprehensive, statewide programs provided by TSBVI.

Key Words: blind, deafblind, comprehensive programs, curriculum development, staff development, outreach.

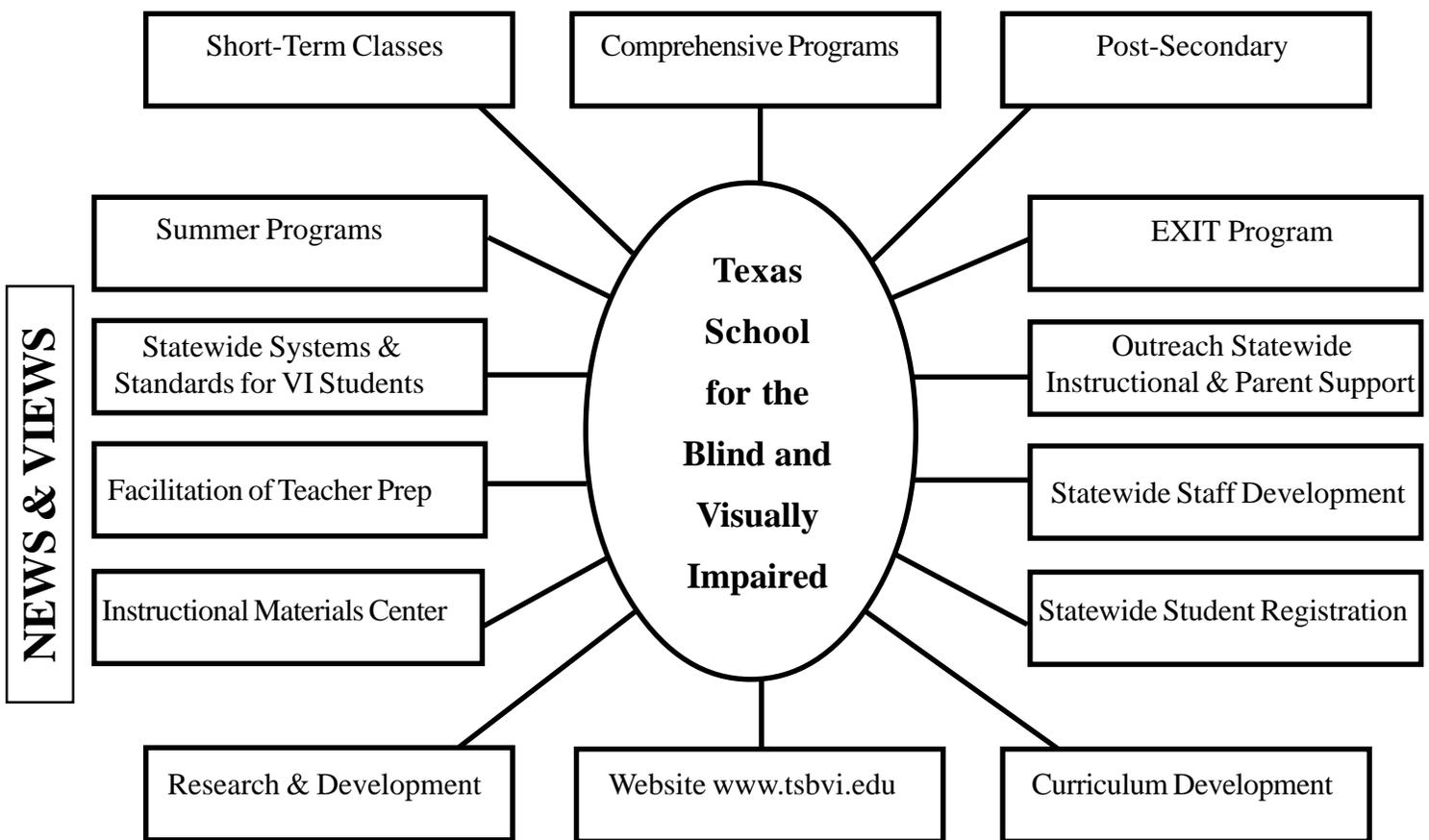
In the last See/Hear issue, I described on-campus programs for blind and visually impaired students at the Texas School for the Blind and Visually Impaired (TSBVI). These educational services are, for the most part, designed to provide intensive specialized services that may be difficult for the local school to provide. In this final segment of the series, I want to describe the ways in which TSBVI can enhance the education of children who never come to campus.

If a local school district has the capability and desire to provide an appropriate education for a blind or visually impaired student, then in most cases there is no reason for the student to come to the TSBVI campus.

In a previous article, I described TSBVI as being the center, or “hub” of services for all students in the state. There are few places in Texas that can assemble to depth and breadth of expertise that TSBVI has. Thus, the school is called upon to offer its services to students throughout the state. In fact, the Texas State Legislature has included language to this effect in the State Education Code. The service needed by an individual student will vary from none to substantial, and the comprehensive programs for off-campus students makes it possible for TSBVI to effectively supplement the work of a local district.

The following chart illustrates a variety of programs at TSBVI. There was a time during the evolution of TSBVI when many of these additional programs were in place, but the primary function remained that of a residential school for blind and visually impaired students. However, in recent years, as the services to off-campus students has grown and proven its effectiveness, TSBVI now values equally all the services this chart describes. If our major purpose is to provide educational services that local school districts have difficulty in providing, then we must offer a “menu” of opportunities for students to benefit from both on-campus and off-campus services.

TSBVI in the 21st Century



The boxes around the periphery of this diagram represent programs and services that are either traditional, not quite new any more, or very new. A full explanation of all the boxes would require many pages, so I will only briefly describe each. The diagram and boxes should help explain why TSBVI has become a vital statewide resource for all blind and visually impaired students in Texas.

SHORT-TERM CLASSES

TSBVI did not originate the idea of providing short-term classes during the school year, but we have improved and expanded the concept. Students enrolled in local schools have the opportunity to come to the TSBVI campus for a short time (two days to one week) and receive intensive instruction in a particular area. By providing some tutorial help during the student's time at TSBVI, we can assure local school districts that the student will not fall behind in classes taken in the regular school.

COMPREHENSIVE PROGRAMS

TSBVI continues to offer students their on-campus, residential program. It is rare for a student to stay at TSBVI for more than three years. When a student is admitted to TSBVI, the local school district is informed that we will provide educational services based on specific needs of individual students. These needs are determined by the parents and local school district. When those needs are met, it is our intention to transition the student back to her local school. Since local schools have become quite good at adapting and offering appropriate academic subjects, TSBVI's primary focus is on educational needs that are not related to academic courses, but rather on instruction in the expanded core curriculum areas. We are also able to provide intensive instruction for students with specific challenges such as those needed by students with deafblindness or multiple disabilities.

POST-SECONDARY

TSBVI and the Texas Commission for the Blind now offer a collaborative transition program for high school graduates. Young people who have spent their entire school lives in regular schools will have first priority, because it is often very difficult for local schools to offer instruction in nonacademic areas, such as living skills, social skills, career education, assistive technology, etc. It is modeled after the highly successful Living Skills Center for the Visually Impaired in California.

SUMMER PROGRAMS

Each year TSBVI offers enrichment classes for students who spend the academic year in their local schools. There are usually about 12 different programs, ranging from one week to six weeks. While the programs offer many different themes, the emphasis for high school students is vocational education and work experience. Usually about 250 students are served.

STATEWIDE SYSTEMS AND STANDARDS FOR VI STUDENTS

TSBVI has developed "Quality Programs for the Visually Impaired" (QPVI), a system that local schools use to determine the effectiveness of their programs for blind and visually impaired students. QPVI has assisted many local districts in Texas, and has recently expanded to other states. It is primarily a self-study process that requires schools to carefully and honestly evaluate the services they are providing to blind and visually impaired students.

FACILITATION OF TEACHER PREPARATION

Texas, like all states in the U.S., has suffered from a chronic shortage of teachers for visually impaired students, and orientation and mobility instructors. In response to this problem, the Texas State Legislature designated TSBVI as the lead agency in facilitating efforts to minimize the shortage of teachers. TSBVI contracts with universities in the state in order to accomplish this. Also, TSBVI has developed an outstanding mentor program, pairing experienced "master teachers" with new teachers.

INSTRUCTIONAL MATERIALS CENTER

In its role as a statewide resource, TSBVI is now the Statewide Instructional Materials Center for products available from the American Printing House for the Blind and purchased through the Federal Quota system.

EXIT PROGRAM

This is a special program designed to meet the needs of students who are within several years of graduation. It provides opportunities for community-based programming and career exploration. Students live in more home-like settings and have instructional emphasis on independent living skills needed for successfully moving into more independent adult settings.

OUTREACH STATEWIDE INSTRUCTIONAL AND PARENT SUPPORT

The Outreach Department at TSBVI is well-known throughout the U.S. as a model in providing technical assistance to students, teachers, parents, and administrators. There are two teams in the Outreach Department. One specializes in visual impairment, and the other in services for deafblind students.

STATEWIDE STAFF DEVELOPMENT

TSBVI, through its Outreach Department, provides professional development for all teachers in the state. Opportunities for professional growth for educators and administrators are provided in a variety of formats, ranging from statewide conferences to interactive video programs.

STATEWIDE STUDENT REGISTRATION

The Texas Education Agency contracts with Education Service Center XI in Fort Worth for the completion of a yearly statewide registration of all blind and visually impaired students. The Service Center has subcontracted this task to TSBVI. Data from this process is sent to the American Printing House for the Blind, where the quota fund for Texas is established. Student Registration data may be used for research, with the permission of the Texas Education Agency. Additionally, TSBVI is now compiling the Texas Deafblind Census for submission to OSERS.

RESEARCH AND DEVELOPMENT

TSBVI is often called upon to provide access to students and teachers for studies involving technology projects. We strongly support legitimate research efforts of colleagues, and we make our campus available as long as research does not conflict with the purpose for which students are at TSBVI. Internal research and development is conducted on an ongoing basis by our Curriculum Department.

WEBSITE

The TSBVI website (www.tsbvi.edu) began as a project to share information and resources statewide. Currently it receives about 1,500,000 hits per year, making it one of the most used websites related to the education of blind and visually impaired students. While used primarily in Texas, it has become a major source of information and learning for many countries throughout the world.

CURRICULUM DEVELOPMENT

TSBVI's Curriculum Department works with the entire school to determine the need for new curriculum guides. These are developed first for the teachers at TSBVI, secondarily for teachers throughout Texas, and finally for the entire world. We have been blessed by having some of the best writers of curriculum in the U.S. Our publications are "best-sellers" in the profession because they are practical, easily put into practice, and written by teachers.

I would like to emphasize to you that none of these outside boxes existed 15 years ago. TSBVI did not assume these responsibilities in order to survive. Rather, TSBVI carefully analyzed the current status of education for blind and visually impaired students, attempted to project into the future, and developed programs designed to provide every child in Texas an equal opportunity to education. These programs illustrate the partnership that continues to grow between local school districts and TSBVI.

When Planning for Adult Life, How is a “Life-style” Different than a “Program”?

by David Wiley, Texas Deafblind Outreach, TSBVI

Abstract: A discussion about a person-centered or “life-style” approach to developing programs.

Key Word: blind, deafblind, program development, transition, intervener

A few years ago I made a videotape for families and teachers helping young people with deafblindness making the transition from school to adult life in the community. The tape depicts several young adults with deafblindness. One is a young man with Congenital Rubella Syndrome, who is deafblind with additional disabilities, lives with his mother, and has the support of an intervener who comes to his home to work with him for several hours per day. The intervener is paid for through a Medicaid “waiver.”

When the intervener comes to the home, he uses a tactile symbol calendar, made of poster board, Velcro, and homemade tactile symbols to inform the young man of the day’s and week’s events. He then helps the young man take part in meaningful activities in the community and at home. These activities include: making a grocery list; going to the grocery store; making fresh-squeezed juice; doing strength and flexibility exercises; chopping raw vegetables in a food processor; and taking a ride in the neighborhood on a tandem bike. The tape mentions that they often go to a swimming hole in a local creek.

Recently, after showing the videotape to a group of teachers in a rural area, I was asked where the young man lived when I made the tape. I answered that he lived in Austin, our state capital, with more than a million people in the metropolitan area. To this, a teacher replied, “You can find programs like that in big cities, but we don’t have any of those kinds of programs in small towns and rural areas.”

This comment made me stop and think, because I am conscious of the fact that resources are often not distributed equally in all areas. But as I thought, it occurred to me to ask, “What ‘program’ is not available in small towns?” A local man was hired to serve as an intervener, and he and the young man’s mother got together to plan daily activities. The intervener went to the young man’s home to work with him. From there they went to stores and swimming holes, rode bikes in the neighborhood, and did enjoyable activities surrounding food and physical movement in his home and yard. All of these activities were chosen because they are meaningful activities based on the young man’s preferences, which kept him active, motivated, and content. The young man’s support is funded by a Medicaid Waiver available in all the rural counties I was visiting.

What part of that situation couldn’t be done in a small town? All that is needed is posterboard, Velcro, a grocery store, juicer, food processor, exercise mat, bicycle, road, and swimming hole. It could be anywhere.

I think this misunderstanding arose because we have been conditioned to think in terms of programs, a system-centered approach, rather than life-styles, a person-centered approach, when thinking about adult lives for people with disabilities that need extensive support.

SYSTEM-CENTERED PROGRAMS

In the past, it was usual to think about support for adults with significant disabilities in terms of getting into a “program”, and going to the program, a place, to get needed services. These programs might include, day-activity centers, sheltered workshops, residential facilities, supervised recreation centers, therapy centers, supported-living apartments, etc. These programs are created by the “system” of service providers to meet the needs of clients or consumers in the area. Programs that now exist certainly fill a vital role in meeting some people’s needs.

However, programs are usually created to meet the needs of groups of people. Consequently, they are most often found in larger population areas and often are designed to meet the common needs of most people, rather than focusing on individual needs. As a result, in order to gain services, people must qualify as eligible and fit in to the agenda followed by the group. Consequently, some people are unable to get the kind of services they need in the place they want because there are no programs in the area, or the existing programs and the individual are not a good fits.

PERSON-CENTERED LIFE-STYLES

Rather than planning by starting with what programs are available, I prefer to start by asking what kind of life-style and activities the person would like as an adult. The creation of new ways to fund services in the community allows us to plan by discussing preferred life-styles rather than available programs. For over ten years now, support for adults with disabilities can be provided to individuals through Medicaid “Waiver” services. In Texas some of these “Waivers” are called: Home and Community-Based Services (HCS), Community Living Assistance and Support Services (CLASS), The Texas Waiver for Deafblindness and Multiple Disabilities (DB-MD), Community-Based Alternatives (CBA). Waiver Services are designed to be flexible in developing a plan to meet individual needs.

This allows a person-centered, rather than system-centered, planning approach. Rather than asking what programs might be available, transition teams can start by asking, “What are the person’s abilities and preferences? What would the person like to do with his or her time? What kind of support would enable the person to do these things?”

This can lead to solutions like those in the videotape. The young man’s preferences lean toward food and physical movement. On the other hand, unpredictable events (having no schedule, or not knowing what is happening) lead him to become frustrated, agitated, and sometimes self-abusive. Preferred activities include getting, preparing and eating the foods he likes, as well as exercising, swimming, and riding bikes. He needs emotional support in the form of consistent routines, and being informed of what to expect so he can anticipate and look forward to things. He needs guidance and physical support to stay active and accomplish the activities he likes. He needs these activities to be planned for him in a schedule that keeps him interested and involved, and at a pace that leads him to be successful. There is no preexisting program that meets all his individual needs, in any large city or small town. Instead, the people who support him created the life-style.

IT CAN HAPPEN ANYWHERE

I recently made a videotape of another young man who is deafblind with additional disabilities. He lives in a small west Texas town. His parents had applied for him to get services from the Texas Department of Human Services through the DB-MD Waiver. They planned together with his case manager, who works for a service provider organization in the nearest city, and developed an individual plan of care. The service provider hired an intervener in their small town. She comes to his home, does activities with him there, and takes him out into the community. With her support, he keeps a garden in his yard, helps out with domestic chores like laundry, enjoys music-related activities for fun, goes to the park and stores, and volunteers his time at a regional VA medical center, helping his grandfather with Bingo games for older patients. He takes swimming lessons at the local YMCA. He visits with friends at the hospital,

and in his intervener's neighborhood, as well as often running into acquaintances at the Walmart or the pool. This is a life-style he enjoys based on his abilities and preferences. As his Dad says in the video, "We made our own program."

Starting with a life-style: that is how transition planning becomes person-centered. Sometimes the plan may involve taking part in existing programs, if they are available and provide a good fit for an individual's goals. Sometimes teams will need to "make their own program." It can be done anywhere: large cities, small towns, and rural areas. It starts by thinking about life-styles.

When this talk of programs came up, I remembered a poem written by the keynote speaker of one of our workshops many years ago. At the time I first heard it, I enjoyed the poem, but I think I didn't fully appreciate it, because I was still too close to the system-centered approach to planning. I recently reread the poem with a new appreciation. It is called "Beyond Programs".

Beyond Programs: A Parable

By Michael McCarthy

In the beginning, there was *placement*, and lo we were happy when it happened, as placement was not mandated for adults who happened to experience severe disabilities.

And so, we said, this is good.

And placements multiplied and filled the earth.

And then we said, let us make *programs*, which focus on serving clients.

And clients were defined and labeled, and grouped according to their labels and assigned to programs based on their label.

And programs created services for each label, and state agencies developed unit costs for each service.

And programs prospered and multiplied, and we said, this is very good.

And as programs multiplied, a cry arose: Let us evaluate these programs to see how good they really are.

And program evaluation, state regulations, quality assurance, compliance plans, and other program measures were created.

And they multiplied and filled volumes.

And in those times, a person arose who was a client, but who was also a prophet, and said:

"I don't want to be a client,

I want to be a person.

I don't want a label,

I want a name.

I don't want services,

I want support and help.

I don't want a residential placement,

I want a home.

I don't want a day program,

I want to do meaningful and productive things.

I don't want to be "programmed" all my life;

I want to learn to do things I like, and go places, which I like.

I want to have fun, to enjoy life and have friends.

I want the same opportunities as all of you:
I want to be happy.”

And there was a long silence.

And lo, everyone realized that they must look beyond their programs.

But they were troubled, and they asked:

“How can we do this? Would not each person need their own unique program and system of support and his own individual measure of its quality?”

And the prophet replied:

“Even as you say, so should it be done-
Just as you do for yourselves.”

This poem was originally published in *HKNC TAC News*, Vol. 4, No. 1, Spring/Summer 1989. Mike McCarthy is currently Coordinator for Community Education and Outreach at the University of Missouri-Kansas City Institute for Human Development, a University Center on Excellence on Disability. He also serves on the advisory board for the National Technical Assistance Center on Deaf-blindness (NTAC). He tries to stay grounded in the lives of people with deaf-blindness by serving as an advocate and guardian for Calvin.

Solving *Their* Problem: A Strong Recruitment Strategy

By KC Dignan, Ph.D., Professional Preparation Coordinator, TSBVI

Abstract: A discussion of recruitment of VI professionals: how to frame your message to encourage those in related fields to consider VI as a profession.

Key Words: blindness, VI professionals, VI teachers, COMS, professional development, VI teacher certification

Recruiting people into a profession, (or spreading the word about a profession) and encouraging someone to hire a VI professional is long-term event; not something that is usually completed in a day, or a single meeting. However, there are some good strategies to help you. Among the most effective is using your message to help solve *their* problem.

Here is a scenario that you’ve probably experienced: Another educator or therapist seems interested in the student you both serve. She is asking questions beyond just the basic questions. She is asking questions such as “Is braille hard to learn?” or “How does he know which doorway is to the *boys* bathroom?” The people in your world might be different, however, the theme is the same: someone in a related profession expresses interest.

In this scenario, the teacher has been a teacher for about seven years or so. Recent surveys tell us that this is a point when many people changed careers and became a vision-related profession. So, as a recruiter, you start to look for signs of restlessness or curiosity about other professions. Also, you begin to think about the type of teacher or therapist this person is.

- Is she organized?
- Does she seem curious about life and has a history of actively pursuing professional development?
- Does she solve problems using multiple resources; with creativity; even with a bit of flare? And most importantly,

- Does she watch your student with a gleam in her eye, a gleam that speaks of a desire to empower, not to entrap?

If so, it is possible that she is ready for a new challenge. She may be beginning to feel like a change, but does not yet know what that change might be. You can help her to solve her problem; become a VI professional.

No one will step outside of their “comfort zone” or spend precious resources to help *you* solve *your* problem: that of not having enough VI professionals, of having caseloads that are too large. Nor are people interested in retrofitting skills and services because you are not brought into the service plan sooner. People are interested in solving *their* problem. You can help meet your needs by helping them to solve *their* problem.

HOW CAN YOU DO THIS?

You can do this by how you “frame” your message or actions.

Speak from a position of strength

Instead of complaining about how many students or consumers you must work with, invite the teacher to be your partner in serving the wide diversity of students with whom you interact.

Show them the options

If someone is considering a change, help them to see that working in a VI profession is **interesting, stimulating**, and has the appeal of being a bit **nontraditional**. Discuss the satisfaction achieved as a result of knowing that your work makes a difference in children’s lives. You can make it easy for the teacher to see this by inviting the teacher to spend her planning hour, or staff development day shadowing you. Then have fun and show off your students and your profession.

Demonstrate performance

Let directors know how hiring a VI professional will help them solve a problem they are dealing with; how hiring, or getting someone in training will either improve student performance or save the district money by having more “in-house” services.

When you “frame” your message from the point of view of the listener, you will become a stronger communicator, and a better recruiter. Oh yes, and will help solve *Your* problem.

Texas residents who are interested in working with children with visual impairments have three options for instruction. All of the programs listed require a bachelor’s degree. Certification as VI teacher requires a teaching certificate in some other area. O&M specialists are not required to have a teaching degree. Tuition stipends are available for Texas residents.

- Texas Tech University offers on-line instruction.
- Stephen F. Austin State University offers a blend of on-line and interactive TV.
- Region II Education Service Center offers training on alternate years, beginning in June of alternate years.

For more information about programs in Texas, including university websites, you can read the biannual training newsletters at <<http://www.tsbvi.edu/pds/fall01.htm>>. You can also contact KC Dignan, Ph.D. at <kcd@TSBVI.edu>.

For information about training programs outside of Texas, you can visit the University Directory webpage: <www.tsbvi.edu/pds/universities.htm>. You will find information about programs, contact information and web links.

Families of Children with Deafblindness SPARKLE

Project SPARKLE (Supporting Parent Access to Resources, Knowledge, Linkages, and Education) through funding as a Model Demonstration Project for Children With Disabilities has developed a new model of individualized learning for parents of children and youth who are deafblind. This model is unique because it provides information, training, resources, and networking that parents can access in their homes at any time using DVD technology combined with the Internet.

Deafblindness is a low-incidence disability that results in complex needs that most professionals and systems are not prepared to address. Parents of these children are the major factor in their lives and must be especially well prepared to fulfill their critical role in the development and education of their children. Information and training is traditionally available through workshops, conferences, and parent retreats. Yet, many parents are unable to travel to these activities, and much of the information may not be specifically relevant to their child.

The SPARKLE model is the answer for these parents, because it overcomes many training barriers. Parents who participate in this Project view the DVD training program, develop a child profile that individualizes the information to their children, are linked to multiple resources, and network with other parents of children who are deafblind – all this from their homes. Project SPARKLE has proven to be a successful model with 61 families in Utah, Texas, Georgia, and Minnesota. It is now ready to be expanded to additional families in Utah, Texas, Georgia, and Minnesota and to families in new states.

If you are a Texas family with a child who has vision and hearing loss in combination and are interested in participating in this unique training option, please contact Edgenie Bellah, Family Support Specialist with Texas Deafblind Outreach, at 512-206-9423 or email her at <edgeniebellah@tsbvi.edu>.

American Council of the Blind Scholarships On-line

ACB scholarship applications are now available for on-line processing. For the main web page at <<http://www.acb.org/>>, click on the link AMERICAN COUNCIL OF THE BLIND 2004 Scholarship Application and Information to begin the application process. Each year, the ACB provides significant student scholarships for all facets of educational endeavor, encompassing everything from vocational to postgraduate academic endeavor. In 2003, ACB awarded \$38,850.00 in direct scholarships and sponsored recipients as attendees to our national convention in Pittsburgh, PA. Please let students and those who are in touch with students know of the beginning of ACB's 2004 student scholarship availability. If you need in-person assistance in addition to what is offered on the website, please contact Terry Pacheco in the ACB National Office at (800) 424-8666.

New on the TSBVI Website

Have you ever wondered about the process of admission used to place a child at Texas School for the Blind and Visually Impaired during the regular school year? Now you can get more information about that process on line by going to <<http://www.tsbvi.edu/school/comp/primer.htm>> to read "A Primer on Admissions to TSBVI." Are you interested in applying for your student to attend one of the TSBVI summer school programs? Summer school program descriptions and applications may be downloaded by going to <http://www.tsbvi.edu/school/special/summer.htm>>. You may also be interested in learning about the Special Programs being offer this year. Go to <<http://www.tsbvi.edu/school/special/short-classes.htm>>.

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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>

MAKING CONNECTIONS

**A retreat for families of children with combined hearing & vision loss
and deafblindness in the Houston area**

Saturday, March 27, 2004

9:30 a.m. until 6:30 p.m.

HH Ranch - 4000 Greens Road, Houston, TX 77032

(Near Bush Intercontinental Airport)

Sponsored by Region IV Education Service Center,
Texas Commission for the Blind, and Texas Deafblind Outreach

Parents of children with combined hearing and vision loss or deafblindness often need information and support to learn how to support their child's unique learning style.

Brothers and sisters need to connect with other kids who have a family member with hearing and vision loss so they can share the joys and challenges of having a sibling with special needs.

Children with combined hearing and vision loss or deafblindness need opportunities to socialize with their peers and to have an enjoyable outing with their whole family.

Making Connections is a one-day experience for the whole family that combines outdoor fun with learning and support. Making Connections will be held at the HH Ranch, 4000 Greens Road, Houston, TX.

Events for the day will include activities for siblings and parents. Parents will learn more about the combined effects of vision and hearing loss on learning, what can be done to provide a quality program for their child, and resources to help both their school and their family understand the unique issues related to these sensory losses. Information will also be provided to help them think about planning for the future for their child with deafblindness, including the critical transition to adult life from school life.

Travel assistance is available for Families in the Houston Area. Making Connections is provided free of charge to families including lunch. Travel assistance is also available for families to cover the cost of gas. For families who are unable to bring their children with them due to age or medical considerations, reimbursement to help cover the cost of childcare arranged for the child at home is also available.

If you are interested in learning more about this event contact Karen Crone, Region IV ESC at 713-744-6324 or Suzy Scannell, Region IV ESC at 713-744-6315 or Lori Drake, TCB at 713-880-0721.

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TAER 2004 Annual Conference:

Choosing to Grow Through Change Planting Seeds of Knowledge... Harvesting Success!

**April 15-17, 2004
Hilton Airport, San Antonio**

If things aren't changing in the professional part of your life, then you must not be living in Texas right now. Sweeping changes are happening in almost every aspect of our field and we know that many of you are working hard to adjust and realign. This year's TAER Conference is the perfect place to share and gather valuable information like what's new in your agency/school/region; coping strategies for challenging situations; new ideas and programs; as well as the skills and information that you and your colleagues want and need. Plan to attend the entire conference and learn from others as you build new relationships that will broaden your horizons and strengthen your commitment to continue to be the best you can be.

For conference information
or to request a registration form contact:
Neva Fairchild at: <neva.fairchild@tcb.state.tx.us>

Orientation and Mobility Division Pre-Conference Meeting:

Division 9 will be meeting before the TAER Conference. If you are interested in being involved in what is happening in the O&M field on the state and national level, please join us for dinner and a meeting on Wednesday evening and from 8:30 to 11:30 on Thurs. morning.

For more information, including how to register for the pre-conference meeting, please visit the TAER Orientation and Mobility Division website at <www.educ.ttu.edu/Sowell/TAER_O_M_Division/>.

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TSBVI Distance Education

These presentations will be offered through the TETN network at the Regional Education Service Centers. Contact your ESC to learn if they are participating.

The Braille Note

March 10, 2004

Motor Issues for Babies with Visual Impairments

April 14, 2004

For general information contact:
Karen Scanlon at TSBVI,
(512) 206-9314 ,
or email to <karensanlon@tsbvi.edu>.

Texas Focus 2004: The Itinerant VI Professional June 10 & 11, 2004 Wyndham Dallas North by the Galleria

Keynote by Jean Olmstead, author of
*Itinerant Teaching: Tricks of the Trade for
Teachers of Blind and Visually Impaired Students*

For more information, contact
Jim Durkel at <JimDurkel@tsbvi.edu> or
(512) 206-9270

AFB, Josephine L. Taylor Leadership Institute March 5-7, 2004 Washington, DC

Contact: Gabriella Smith,
American Foundation for the Blind,
11 Penn Plaza, Suite 300, New York, NY 10001
212-502-7600 or <afbinfo@afb.net>

INSITE

A Home-Based Model for Infants, Toddlers, and Preschoolers Who Are Multiply Disabled and Sensory Impaired

Six days of training for school and ECI professionals working with families who have children birth through five years of age who have multiple disabilities and sensory impairments. Topics include information on vision and hearing loss, communication development, motor development, active learning, and working with families.

El Paso

March 8-9, 2004

April 5-6, 2004

May 3-4, 2004

Contact: Olivia Chavez, VI Project Manager
Region 19 ESC, 6611 Boeing Dr.
El Paso, Texas 79925
Office (915) 780-5344; Fax (915) 780-5304
e-mail <ochavez@esc19.net>

TSBVI in Austin

May 10-15, 2004

Contact: Beth Bible,
Texas Deafblind Outreach
(512) 206-9103

To request INSITE training in your region,
contact Gigi Newton at (512) 206-9272
<giginewton@tsbvi.edu>.

TSBVI 2004 Summer Programs

Summer 2004 programs at TSBVI are now posted on the TSBVI website under the *Special Programs* area <<http://www.tsbvi.edu/school/special/index.htm>>. Go there to find all our summer programs described, plus the application form to download and mail in. You will also see a contact person and phone number for each program, if you would like to have additional information.

This year we are especially promoting our excellent advanced vocational programs: SWEAT for academic students and WALIC for students with additional disabilities. If you click on the program names, you can watch a brief video of last year's students participating in their jobs, along with the thoughts of the students and their employers.

TSBVI Spring 2004 Short Programs Individual Class Descriptions

February 8-13, 2004 - Middle School IEP #2

February 29 - March 5, 2004 - Technology Week (secondary)

*March 25-28, 2004 - Low Vision Weekend (secondary)

*April 1 - 4, 2004 - High School Independence Weekend

*April 22 - 25, 2004 - Space Vision Weekend (secondary)

May 2 - 7, 2004 - Elementary IEP #2

*Weekend Program: Students miss only one day of school

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**New VI Professionals Mentor Center
April 4-5, 2004**

This special event is meant to provide an opportunity for new VI professionals (TVIs and COMS) to observe seasoned professionals in the classroom setting and have an opportunity to discuss what they have learned. To be eligible to attend, you must be a student currently working on VI or O&M certification, or an instructor who has entered the field within the last three years. Experienced professionals who are new to Texas are also invited to attend. Mentors of these new professionals are welcome to accompany anyone attending the Mentor Center event.

For more information contact Carolyn Perkins at 512-206-9434 or email to <carolynperkins@tsbvi.edu>.

**Council for Exceptional Children
Annual Convention and Exposition**

April 14-17, 2004
New Orleans, LA

Contact: Scott Sparks, program chairperson,
2004 Convention and Expo,
Council for Exceptional Children,
Suite 300, 1110 North Glebe Road,
Arlington VA 22201
888-CEC-SPED or 703-620-3660,
<www.cec.sped.org>

**Second Annual
Assistive Technology Conference**

This conference will include a VI strand.
Region IV ESC, Houston TX
May 7, 2004

To Register: <www.esc4.net>, choose e-Catalog link,
enter Event ID number, choose Search
Contact: Cecilia Robinson, 713-744-6379 or
<crobinson@esc4.net>

**11th Biennial
Statewide Conference on
Education of the Deaf**

**Network and Explore:
Boot-up in 2004
July 26-28, 2004**

**Renaissance Worthington Hotel,
Fort Worth, Texas**

Topics include issues in parenting children who are deaf or hard of hearing, professional development for educators and support staff (reading, communications, sign language, etc.), support services in deaf education, technology, transitional periods and services, excellence in teaching, multicultural concerns, bilingual/bicultural issues, inclusion, teaching students with multiple disabilities, post secondary, parent/infant education, speech and language, various sharing sessions, deaf studies, audiology, behavior/behavior improvement, aural habilitation, assessment, and others.

Contact: Ruth Hicks at 281-634-1543 or
<ruth.hicks@fortbend.k12.tx.us>
for registration info

AER 2004 International Conference

July 13-19, 2004
at the Hilton at Disney Resort in Orlando, Florida.

For more information,
contact Barbara C. Sherr, CMP, Conference Manager

Association for Education and
Rehabilitation of the Blind and Visually Impaired
1703 North Beauregard Street, Suite 440
Alexandria, VA 22311 USA
Telephone: 877-492-2708 or 703-671-4500,
extension 201
E-mail: <bsherr@aerbvi.org>

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**Children's Craniofacial Association
Family Retreat**

June 24-27, 2004
Tempe, Arizona

For more information contact Jana Butera at 800-535-3643 or email to JButera@ccakids.com.

**The 22nd National Cornelia de Lange
Syndrome Conference**

June 24-27, 2004
Chicago Marriott at Oak Brook
Oak Brook, Illinois

For more information visit the CdLS Foundation
website: [http://www.cdlsusa.org/news/
Conference_Info.pdf](http://www.cdlsusa.org/news/Conference_Info.pdf)

**6 th International Moebius
Conference: Texas 2004**

July 9, 10 & 11, 2004
Dallas/Fort Worth, Texas

For information: email to <txmoebiu@flash.net> ,
or visit <[http://www.moebiusysndrome.com/2004/
texas2004.htm](http://www.moebiusysndrome.com/2004/texas2004.htm)>

**8th Annual
Stickler Syndrome Conference**

July 10 - 12, 2004
Chicago, IL.

For more information visit the Stickler Involved People
website at <http://www.stickler.org/>

**New on the
Texas Education Agency Website**

New Commissioner's Rules have recently been made
available on the TEA website. To read these rules go to
<[http://www.tea.state.tx.us/special.ed/rules/
adoptrule.html](http://www.tea.state.tx.us/special.ed/rules/adoptrule.html)>

**2004 National Down Syndrome
Society National Conference**

July 22 - 25, 2004
JW Marriott Hotel - Washington, D.C.

This year's conference will celebrate the 25th anniversary of NDSS and highlight our anniversary theme, "Empowering. Reaching. Achieving."

You won't want to miss this opportunity to learn from top experts, connect with parents and professional from across the country and gather important resources. Teens and adults with Down syndrome and their teenage siblings can participate in an innovative program that builds skills and creates lasting friendships. In addition, this year's conference will feature a special day of advocacy workshops and a congressional reception on Capitol Hill.

Conference and registration materials will be mailed in March. To be added to the conference mailing list, call (800) 221-4602.

**Advocacy, Inc.
Seeks Applicants for
Board of Directors**

Advocacy, Incorporated, the designated Protection and Advocacy (P&A) system for Texans with disabilities, welcomes all nominations for its Board of Directors. Individuals from rural areas, language and ethnic distinct communities, and other traditionally under-served communities are especially encouraged to apply.

To Apply

You may obtain an application from <http://www.advocacyinc.org> or from Shirley DeBerry at (512) 454-4816 or (800) 252-9108

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SEE/HEAR

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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 to <bethbible@tsbvi.edu>.

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